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ABSTRACT

Nine presentations from a conference on advocacy of the legal and human rights of the mentally handicapped are given. Robert Segal considers parents and professionals to be the primary advocates for the retarded, while Virginia Nordin examines the implications of recent court cases for the retarded's right to legal process and redress. The right to dignity is discussed by Marjorie Kirkland, and William Cruickshank suggests that the right not to be negatively labelled is important for the retarded. The right to financial assistance is presented by Mary Wagner. Lynwood Beekman recommends action at the local, county, and state levels to insure the right to education for the handicapped. Lorraine Beebe delineates the right to community services such as appropriate physical and mental health care. Inadequate finances and staff are seen by Lawrence Turtond to result in a failure to provide the retarded with the right to adequate treatment in state institutions. Robert Burt considers questions implicit in the right to marry and the right of choice regarding sterilization. Reports of seven group workshops which discussed the presentations are given, as is an evaluation of the conference. (DB)

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Advocacy for the Legal and Human Rights of the Mentally Retarded

Proceedings of the Advocacy Conference

Ann Arbor, Michigan

June 2, 1972

Editor: Robert M. Segal

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INSTITUTE FOR THE STUDY OF
MENTAL RETARDATION AND RELATED DISABILITIES
THE UNIVERSITY OF MICHIGAN • ANN ARBOR, MICHIGAN

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ADVOCACY FOR THE LEGAL AND HUMAN RIGHTS OF THE MENTALLY RETARDED

The Proceedings of the Advocacy Conference of the
Institute for the Study of Mental Retardation
and Related Disabilities
Ann Arbor, Michigan
June 2, 1972

Edited by

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INTRODUCTION

. Because the Institute for the Study of Mental Retardation and Related Disabilities has been for some time concerned with the issue of the legal and human rights of the mentally retarded, it conceived of the idea of holding an all day conference on the subject.

The purpose of the Conference was to bring together professionals, parents and retarded adults to discuss methods of securing appropriate legal and human rights for the mentally retarded and to propose methods and strategies of dealing with the violation of these rights.

Two other organizations involved with programs and services for the mentally retarded were also interested in these issues and expressed a desire to co-sponsor such a conference. The Michigan Association for Retarded Children and the Michigan Chapter of the American Association on Mental Deficiency agreed to provide some limited financial support toward the implementation of the Conference. The Conference was held on June 2, 1972 in Ann Arbor, Michigan at the University of Michigan.

The format of the Conference was designed as follows: Brief 15 minute panel presentations were given by knowledgeable professionals and parents vitally interested and concerned about the human rights of the retarded. The focus of the areas discussed by the panelists were: 1) Advocacy; 2)The right to dignity; 3) The right not to be labelled; (4) The right to financial assistance; 5) The right to education; 6) The right to Community services; 7) The right to treatment in state institutions; 8) The right to marry and the right of choice regarding sterilization; and 9) the right to legal process and legal redress.

After the panel presentations the floor was open to questions and discussion.

After a lunch break, the Conference resumed for pre-planned workshops. In an effort to insure that there was a blending of persons representing various disciplines and that many different areas concerning legal and human rights would be covered and discussed, participants were pre-assigned to one of the afternoon workshops. One of the panelists who

spoke in the morning session served as resource person in the workshop. The first 45 minutes of the workshops were structured to cover the topics that the panelist had presented in the morning session. (The panelist, as the resource person, was given the opportunity to expand on his topic if he so desired) The remaining hour and fifteen minutes permitted the workshop group to cover other areas that were of concern to the participants.

At the conclusion of the workshops the audience as a whole reassembled to hear brief reports describing the content and interaction of the afternoon workshops.

A total of 143 persons representing professionals, parents and retarded adults attended the Conference. A review of the evaluations of the Conference submitted by the participants at its conclusion indicated that the Conference was considered a challenging and rewarding experience and that it carried out its objectives quite successfully.

Robert Segal, Ph.D.
Conference Chairman
Institute for the Study of Mental
Retardation and Related Disabilities

ADVOCACY FOR THE LEGAL AND HUMAN RIGHTS OF THE MENTALLY RETARDED

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and Related Disabilities
Associate Professor of Social Work
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Goethe said, "If you treat an individual as he is, he will stay as he is, but if you treat him as if he were what he ought to be, he will become what he ought to be and could be."

Today we are meeting to discuss the right of the mentally retarded to be what he could be. We are discussing his "right to be human".

The right to be human rests on the one all inclusive right -- the right to live with dignity and with the freedom to develop to one's fullest potential.

This human right, based on the principle of equality which is applicable to all citizens. It is a democratic principle which too often has been generally violated in relation to the mentally retarded.

Today we will be focusing on the securing of these rights -- of the legal and human rights of the mentally retarded. We will be examining many areas which are of deep concern to us. The right to education, the right to treatment both in the institution and in the community, and the right to financial assistance. We will also discuss other rights such as the right to marry, the right of choice regarding sterilization, and the right to legal process and legal redress.

But beyond talking about the legal and human rights of the mentally retarded we will be discussing the equally important concept of advocacy. An advocate is described as "one who pleads the cause of another." An advocate is a defender "an individual who upholds a cause or a proposal. He is one who takes a stand and publicly pleads for the support of a given cause."

Many parents of the mentally retarded and many professionals working in the field have expressed intense indignation about the way our society has treated the retarded. They have expressed impatience and concern about the community's failure to meet the needs of the mentally retarded. Have they, however, been advocates for the mentally retarded? To what extent have the parents of the retarded and the professionals gone beyond mere

redundancy of complaining to take affirmative action so as to effect social change on behalf of the mentally retarded?

While from an organizational perspective this is laudatory and commendable, one must ask is this sufficient? Do we as professionals or parents or friends of the retarded tend to feel complaisant because we are assured that these organizations are speaking out for us.

Individually what is our responsibility as advocates for the mentally retarded? We professionals glibly condemn the service delivery system and organizational structures, and at times perceive it as an adversary for its failure to provide the quantity and quality of services that are so urgently needed for the mentally retarded. As part of that system to what extent have we attempted to speak out against the inequities perpretrated against the retarded in that system. Have we demanded that the system cease and desist any activities that stultify, or demean the retarded? If we have not assumed the advocate role while being part of that system then might we too not be considered the foe of the retarded?

Parents and friends of the mentally retarded condemn society for its rejection and stigmatizing of the mentally retarded. As members of society, do they speak out against the prejudical behavior of society? Do they openly demand that the retarded be treated with dignity and equality? If they do not, have they not silently joined forces with those who are opposed to serving the retarded?

We need more than indignation and concern on the part of parents and professionals to right the wrongs of the retarded. We need tenacity. We need courage. We need to be advocates. We need to speak out individually as well as collectively wherever we encounter injustices to the retarded. We must go beyond speaking out. We must act. We must develop the skills and the strategies to effect social change on behalf of the retarded.

We must resist the pressure placed on us to "be positive" or to "be understanding of the complexity of the problem". We are told the system cannot be changed quickly and that it is professionally and politically dangerous to attack the system or governmental structures that are not meeting the needs of the retarded. We must be leery of such cautious guidelines for while these words may indeed be wise and provide us with valuable, guidance, these suggestions may debilitate action for it tends to reinforce our latent fear of rejection or provoke our anxiety which often leads to conformity and commission. By failing to be the advocate of the

retarded even at those moments when there is professional and personal risk at stake, we may appear to join forces with the conscious and unconscious "enemies" of the retarded. Our failure to accept the advocate role when it really counts may force us to recognize the sad truth in the wise words of cartoonist, Walt Kelly, Pogo's creator, who said, "We have met the enemy and he is us."

At this Conference we will be exploring then not only some of the basic issues that confront the retarded, but what we as professionals or parents can do about safeguarding these rights. The advocate has various alternatives to utilize in his efforts to safeguard the legal and human rights of the retarded. He can seek legal remedy through due process of the law. He can seek political influence to effect positive changes in administrative procedures within a service delivery system. He can use personal influence to effect needed changes in programming. He can clarify issues and provide reliable facts and basic information to change social attitudes toward a more positive perspective about the retarded. He may even use such measures as demonstrations, marches, or sit-ins, which at times have proven to be effective levers for change. Whatever course of action the advocate chooses it should be related to appropriate timing and implemented in such a way so as to assure a positive outcome. Advocacy implies action leading to positive change.

What are some of the difficulties that inhibit the advocate role on the part of professionals and parents?

Many professionals find the advocate role an unfamiliar and uncomfortable one. Professional education tends to support consensus thinking and opposes the conflictual approach. Social workers in their graduate training for example, are often taught in their field work experiences how to conform to and to carry out agency policy. A student and even a new employee is considered competent and skilled when he can consciously and successfully incorporate agency policy into his practice. When the merit of agency policies are openly questioned or criticized, the student or staff person is usually considered to be a "trouble-maker" and is either counselled out of the program or asked to leave the agency.

If a professional continues to assume the advocate role and is labelled

a "trouble-maker" he may jeopardize his job future and limit his opportunities for job promotions and advancement.

Some agencies are concerned about staff criticism of systems that provide money for their programs. Rather than jeopardize their funding source, the agency may directly or subtly instruct its staff to be more involved in carrying out the direct services of the agency and less involved in examining the policies established by the funding source even if these policies may adversely effect the welfare of the client.

It is often easier for professionals not to play the advocate role for such a role is often an unfamiliar and difficult one. Professional education tends to focus on learning traditional concepts and accepting the status quo. As a result, most professionals, lacking the frame of reference or the skills to carry out the advocate role, tend to view their primary responsibility as a dispenser of service. The professionals are few who go beyond the clinical or educator role to critically examine the service delivery system and to attempt to effect that system in a positive way so as to better serve his client.

Unless professionals can be protected against recrimination or "punishment" by their agencies when they attempt to advocate on behalf of a client's grievance, few will attempt to exert appropriate measures to help those who can least help themselves. Professionals may look to their professional organizations to carry out the advocacy role but too often these measures are too diffuse and tend to be centered more on the questions of policy and ethics rather than dealing with the nitty-gritty of the matter. Professional associations do serve as another force amongst the various counter forces that attempt to effect change, however this avenue does not relieve the professional from having to take stands "on the firing line" - back home in his own agency where the specific trouble may lie.

Parents who wish to advocate for their child or who wish to challenge agency or programmatic decisions that effect their children are often inhibited from doing so for fear that the very service which they may be critical of may be closed altogether to them. Parents have told me that when they attempted to complain about poor programs or inadequate services they were told by the staff of community based programs or the superintendents of state institutions that if they didn't like the services they could take the child out of the program. With little alternative care available for their children, parents have learned that it was better to keep quiet and accept

inadequate care than to face the dilemna of no care at all. This threat and fear has done much to stifle open criticism on the part of parents regarding their responsibility to "speak out" on behalf of their children. Understandably they tend to look to the Associations for Retarded Children to fight for them and the Associations have fought well, again usually on policy matters effecting large numbers of retarded persons. They could not begin to fight on a case by case basis. If, however all parents individually, and collectively, directly spoke out when the rights of their children were being ignored, the system would have to face this confrontation and examine the merits of each and every case, as it should.

To be an advocate, then, is a most challenging and often painful process for both parents and professionals. We may choose not to advocate but in so doing we choose not to be full men and women for we are indeed our brothers and our children's keeper. An ancient rabbi, thousands of years ago asked these provocative questions: If we are not for ourselves, who will be? If we are only for ourselves, what are we? These questions still confront us today for what are we as humans if we are only for ourselves?

THE RIGHT TO LEGAL PROCESS AND LEGAL REDRESS

Mrs. Virginia D. Nordin
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What I would like to talk to you about is how the legal system can respond to the legal problems of the mentally retarded. Just by way of quick background, I'd like to say that about two years ago I participated in a conference on the legal rights of the retarded from much the same point of view. We were talking then a great deal about labelling and focused on the case of Hobson vs. Hanson which had abolished the tracking system in the Washington, D.C. school system. At that time I found myself predicting that the legal system might not respond too well to the problems of the mentally retarded. I thought that the proper expert witnessess might not find their way into court and that they might not be used adequately, I was afraid that the form of the legal action might be picked up by those lawyers who would turn it into malpractice suits against educators and other professionals. I thought that the courts might look at this very complicated and intricate problem and say, "Yes, it's a problem, but we will turn it over to the administrative agencies since some cases with that sort of language have come to us as a result of desegregation cases." Lower courts have said "look at all the problems the Supreme Court got us into by saying that the courts had to desegrate the schools and the courts are not set up to do this kind of administrative job. So, we will leave it to HEW or whatever other administrative agency is appropriate."

Well, I'm happy to say that that has not been the response of the legal system. I think the legal system has responded beautifully to this particular problem and has shown that court cases can be used very effectively and very practically by those interested in protecting and expanding and establishing in society the legal rights of the mentally retarded.

I am not going to talk about labeling and the problems of misclassification, nor am I going to talk about the right to an education, centering around the Pennsylvania case. Both those topics will be ably covered here this morning. What I would like to talk about is the additional rights which the mentally retarded are beginning to ask for. I would like to pose the question, "What are the constitutional rights of the mentally retarded?" Fortunately, I need not try to answer that question all by myself. There are a number of cases which have been filed around the country in the wake of the labeling cases and the right to education cases, which clearly plowed the first furrows. The first binding decision in the first of these cases was handed down a little over a month ago. The name of that case is Wyatt, et al v. Stickney, M.D., et al, and it was Civil Action No. 3195N in Alabama. Also known as the Partlow decision. The case was decided on April 13, 1972. Interestingly enough, this action was not brought originally on behalf of the mentally retarded. It began as a suit by disgruntled and dismissed employees at Bryce Hospital, one of Alabama's two large mental hospitals. The employees were objecting to their severance from employment without notice or hearing. As a subsidiary cause of action, they alleged the layoff threatened the quality of care at Bryce and denied patients their constitutional right to treatment. Initially only mentally ill were included in this case, but eventually mentally retarded and their right to treatment were also added to it as a class. Fortunately, the attorney for the plaintiffs realized the national implications of the suit he was bringing and enlarged it to a class action. Fortunately, too, and extremely significantly for the future of such cases, the judge allowed a number of organizations, including the United States through the Justice Department, to act as amicus curiae. This Latin term translates literally as "friend of the court," and it refers to the process by which interested parties may appear as witnesses and file briefs, even though they have no direct interest in the case as either a plaintiff or a defendant. In this case, presentations were made by the American Psychological Association, the American Ortho-Psychiatric Association, the American Civil Liberties Union, and the American Association on Mental Deficiency. Judge Johnson, being particularly enlightened, granted the friends of the court in this case an extraordinary opportunity to participate

fully in the proceedings on the presentation of witnesses and cross examination of other participants. This is a standard which is important not only because of the final outcome of the case, but because it indicates and incorporates the type of expert evidence that should be employed in any case in which the constitutional rights of the mentally retarded are to be adequately explored. The Court also took a somewhat unprecedented step in allowing the plaintiffs and the friends of the court to tour the Partlow State School and Hospital, a public institution located in Tuscaloosa designed to habilitate the mentally retarded, prior to the hearing. The fact that this was done led to a number of stipulations between plaintiffs and defendants; that is to say, they agreed on certain conditions and standards which they presented to the Court for approval. Three days were spent in hearing the mental retardation aspects of this case. In an interim order, the Court recognized the urgency of the situation and issued an emergency order stating, "The evidence ...has vividly and undisputedly portrayed Partlow State School and Hospital as a warehousing institution, which because of its atmosphere of psychological and physical deprivation is wholly incapable of furnishing habilitation to the mentally retarded, and is conducive only to the deterioration and debilitation of the residents. The evidence has reflected further that safety and sanitary conditions at Partlow are substandard to the point of endangering the health and lives of those residing there, that the wards are grossly understaffed, rendering even simple custodial care impossible, and that overcrowding remains a dangerous problem often leading to serious accidents, some of which have resulted in the death of residents." Wyatt v. Stickney, March 2, 1972, unpublished interim emergency order.

The interim emergency order went on to require the State to bring the Bartlow Home up to safety standards immediately, For example, changes to make the building fire safe had to be implemented immediately, and in another unusual move the State ordered the immediate hiring of 300 new aide-level employees within 30 days, stating in this connection that the Civil Service should be by-passed. Interestingly enough, within ten days after the order was made public, more than 1000 persons applied for jobs and the quota was met.

The final decision in this case, handed down in April, provided standards which the Court considered to be minimumally constitutional, medically adequate treatment for the mentally retarded. It also established a detailed procedure for implementation. Some of the detailed requirements are the following: (a) minimum staffing standards; (b) protections to insure humane psychological environment; (c) detailed physical standards; (d) minimum nutritional requirements; (e) provision for individualized evaluation of residents; (f) habilitation plans and programs; and (g) appropriate transitional care.

There are two additional and very important provisions I would like to discuss a little further. The judge established a new right for mentally retarded persons, and that is the right to the "least restricted setting necessary for habilitation." This means that there is an additional requirement beside the very important right to education, which will take mentally retarded people out of warehousing institutions and put them into the adequate interim community care facilities which can best promote their continued progress.

Second, the Court prohibited by its order "institutional peonage." This refers to uncompensated-for labor by mentally retarded persons. This is important because the principle established here has also been echoed in other cases which ask monetary damages for the unpaid work done by mentally retarded persons. There have been some additional cases filed, specifically in Tennessee where they are asking $5,000 in wages plus interest and $3,000 in back wages in a class action. To telescope a very important issue, this means that lawyers can and will be attracted to these cases on the bases of contingent fees if there is a possibility of recovery based on the peonage restriction. It is interesting to note that in the Wyatt case, the Court also allowed reasonable attorneys' fees for the plaintiffs' lawyers which would be paid by the defendants.

Another imaginative and precedent-setting position taken by the Court was the establishment of a Human Rights Committee for the Partlow Institution. "The Human Rights Committee will review all research proposals and all rehabilitation programs to insure that the dignity and human rights of patients are preserved." It will advise and assist patients who allege that legal

rights have been infringed or that mental health boards have failed to comply with judicially ordered quidelines. Interestingly enough, a patient is included on this committee.

The Court also ordered that Partlow hire a professionally qualified and experienced administrator within 60 days, and that a follow-up implementation report be filed with the Court in six months.

I believe that this case will be as significant in the field of mental retardation as was Brown v. The Board of Education in desegration, and Gerald Gault in juvenile rights, and the Pennsylvania case in the right to education, and the California cases in the labeling area. It is particularly significant because of the amount of administration the Court has taken unto itself, and the involvement in the detail and the learning in the area. It is an extremely heartening decision. In a similar conference I reported that I felt there was a tension between the employment of experts and the requirement of the Court to make simply legal decisions. It seemed to me that the difficulties inherent in weighing technical evidence and in finding the proper expert opinion might work to the detriment of the plaintiffs, once they reached a court setting. Fortunately for us all, the first judge to handle one of these cases has done so in an unusually able and brilliant manner. I think we can all be grateful for him and we can look forward to further developments.

Other cases which raise similar issues include New York State Association for Retarded Children v. Rockefeller, 72 Civil Action No. 356 (ed New York), in which the complainants in a class action seek to have conditions at Willowbrook declared in violation of the constitutional rights of the residents. Specific violations of the 1st, 8th, and 14th Amendments is alleged. The plaintiffs also ask that the Court set minimum standards for adequate treatment and require implementation, that the Court order compensatory treatment for regression and deterioration already suffered by plaintiffs, that the Court enjoin the appropriation of more money for Willowbrook until community facilities have been developed, and enjoin the admission of any more residents until the Institution meets constitutional standards, and that the Court appoint a receiver or master with the necessary authority to oversee and implement other orders of the Court. Specific

allegations included lack of training to walk, talk, feed themselves, and use toilets; children left unattended; improper medical care; forcing parents to consent to experimental programs; overcrowding; prohibitions against mail; virtually no furnishings; inadequate clothing; incompetent, inadequate staff, brutal conditions for solitary confinement; use of ties, straps and strait jackets for long periods of time; forcing residents to perform involuntary labor, no schooling; no speech therapy; inadequate sanitary conditions; and unauthorized medical experiments.

Another right to treatment class action case is Ricci, et al v. Greenblatt, et al, Civil Action No. 72-469F (Middle District of Mass.) Here again we have a 46-page complaint against the operation of Belchertown. And another case is Bornham v. Department of Public Health in the State of Georgia, Civil Action No. 16385 (N.D. of Georgia), a right to treatment case alleging violations of the 5th, 8th, and 14th Amendments, seeking a preliminary permit injunction declaratory judgment.

Class action alleging involuntary servitude was filed by patients in Tennessee. The case name is Townsend v. Treadway, Civil Action No. 6500.

These cases are reaching the Courts and they are being decided on. That means that people who raise these questions will be better heard because people will look to the courts.

Now there is a large unresolved problem, and that is, who pays for all this. (I hope we're going to hear more about this later from our panelist from the Federal government.) The Partlow case is on appeal. Funding of programs may be taken up as one of the points as well as whether the Court exceeded its judicial function in setting down this very detailed administrative plan and bypassing the civil service by requiring the hiring of an administrator in sixty days. Ali of which were very unusual actions. However, this yet remains to be seen. I think that all of this is just extremely heartening. I think again we must be grateful to the individual lawyer who recognized how important the Partlow case was to the public interest, and to the lawyers in Washington who took up the case, and to the foundations which support them in what they do, and to above all, the judge in his brilliant and very able handling of the case. I think it has proved that the legal system can respond and will respond very strongly and that you can depend on it.

THE RIGHT TO DIGNITY

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It has been said that a conference is a meeting at which people talk about what they should already be doing. Certainly, in speaking of the human rights of the retarded that is only too true. At the risk of unnecessary repetition, I should like to emphasize that we are talking not about privileges--which are given or withheld--but about rights, which are inherent in the human estate under our Constitution.

That this is not generally understood can be illustrated by a remark made at a meeting on human rights especially in relation to institutional care held a couple of years ago. A Superintendent, during the discussion, rose and said sincerely, but unctuously, "I give my children their rights." Whereupon a lawyer jumped to his feet and said coldly, "You don't give anybody his rights--you can only take them away."

How often do you and I who work with and on behalf of the retarded take their rights away, unwittingly, sometimes in the name of protection, and sometimes because their rights are thought to be different from the rights of other human beings?

Thomas Paine has pointed out the meaning of the constitutional guarantee of the principle of equal rights. He said, "The principle of equality of rights is quite simple. Every man can understand it...Where the rights of men are equal, every man must finally see the necessity of protecting the rights of others as the most effectual security of his own." So we're really talking about protecting our own rights, too.

One of these rights is the one without which the others are shams: the right to human dignity. What is dignity? It is hard to define, but it is easy to recognize when our own has been violated. One definition is "self-possession and self-respect; importance and worth." Self-possession: owing one's self. Have you ever felt you didn't own yourself--that you had been taken over by someone else, perhaps an autocratic boss or a domineering caretaker when you were sick? How much do we allow the

retarded to possess themselves? Self-possession requires an appropriate degree of self-determination.

I had a marvelous experience last year of spending three days with a group of young retarded adults while they talked about what it means to be retarded. As an example of what self-possession means, when one can't take full responsibility for one's self, one young man said, "We wish parents, teachers, and others who lead us would listen to what we have to say and let us disagree even if we don't get to do things our way." Don't you find it necessary to express your adverse opinion even when you know you will have to give in? This is one of my ways of maintaining my dignity at times.

Dignity involves self-respect, but whence comes that respect for one's self? It originally comes from other people. Without the respect of meaningful others, it would be difficult to develop it. This means you must respect the retarded persons with whom you work, no matter how severely handicapped they are. Remember, this is a right they do not have to earn.

This can be a difficult demand on the teacher, attendant, or whoever. We all have our likes and dislikes. I have noticed some workers respond very favorably to a grossly handicapped person from whom many others turn away. Why? Because, to coin a phrase, beauty is in the eye of the beholder.

Since this is true, it behooves each of us to examine not only the persons we like or dislike, but to examine ourselves. What is there in us that makes us dislike certain people and not others? Are the values we hold for ourselves valid for them? It is often true that the thing we dislike in someone else is the same tendency within ourselves which we don't like.

Liking--or loving--is an important ingredient in respect, but it is not enough. Paternalism or maternalism is not dignifying. Informed, optimistic and realistic expectations are also vital. Have you even had the good fortune to have a teacher, boss, friend or co-worker who expected more of you than you usually exhibited? Did you find yourself rising to that expectation, sometimes even surprising yourself?

On the other hand, have you ever suffered the suffocating feeling of having too little expected of you? There is a fine line between expecting too much and expecting too little, but the more you know yourself, and the

more you listen to the retarded persons in your care, the more skillfully you will tread that fine line. To quote Elbert Hubbard, "It is a fine thing to have ability, but the ability to discover ability in others is the true test." That expectation that the individual can and will grow plus the love or liking for him as he is will express your recognition of his human dignity.

I want to state that I can only say "amen" to Mrs. Nordin's description of the legal system's response to the mental retardation court cases which have recently been acted on and some of which are still in the court. I would like to say that this reminds me of a story which you probably know of the farmer who bought a mule from a neighbor. The neighbor promised him that the mule always did what you told him. The farmer was a little bit skeptical about this since that's not the way mules usually act. The owner of the mule insisted that this was true. So the farmer took the mule home and he got him back in the field and he said, "Get up," and the mule just stood there. And he kept on and the mule just stood there acting like mules generally do. So, the farmer went to his neighbor and indignantly said, "What do you mean? I thought you said that mule would do what I told him to?" He says, "Yeah, but you have to take this 2 by 4 and hit him on the head and attract his attention and then he'll do as you say."

The two young lawyers from the Justice Department who were assigned to the Partlow case, had hardly ever heard of mental retardation before their assignment to this case. However, they soon got very much involved as most people do, once they got into the questions and problems of mental retardation. They then became ardent advocates and they came charging back to the various agencies of the federal government that were concerned with mental retardation and said, "Why in the world aren't you all telling people how bad these situations are? Why don't you tell these horror stories?" Well I don't believe there's a day that goes by somewhere in this nation that the newspapers don't spread a horror story about a local program for the retarded. We're innundated with sheets out of the newspapers from various parts of the country. The trouble is to get the mule's attention. Now when the courts speak, by golly, that is a 2 by 4 that really works and people start hearing it. And this to me is the primary value of these court cases. But as Mrs. Nordin has pointed out, it raises a myriad of questions. From one single Fed's point of view, (I wouldn't dare speak for

all Feds, I wouldn't even dare speak for HEW,) but from my point of view, I would like to share some of my thoughts as I look at the possible implications and outcomes of the various cases that are pending. The Partlow case is still pending since it is to be appealed. There is also the Willowbrook case, the Belchertown case in Massachusetts, and by tomorrow, there'll probably be three more.

In the first place I would like to emphasize something that people sometimes forget, especially when they're talking about the retarded. A right is not something you give somebody. A right is inherent under our Constitution. If you are under the Constitution of the United States, you have certain rights. Nobody can give you those rights; they can only take them away. And that is what we've been doing traditionally to the retarded; we take them away. Now this is quite a different thing from giving people what is rightly theirs. The Partlow case as was mentioned brought up the right to treatment. Mrs. Nordin mentioned that 49 minimum standards were set up. I'd like to just briefly tell you how those standards were arrived at. Some of you may know that there has been for several years a very concentrated effort to set up a statement of standards of residential care for the retarded. The document has been drafted and is in the process of being field-tested. But I don't think anyone would say that there is a real consensus of approval for all of those standards. Until it has been field-tested it cannot be claimed to be a set of standards that anyone can completely rely on. And in the Partlow case, those standards were looked at, and they were the basis for the 49 determinations that were made by the court. But in the first place they had to be translated into numbers, which had been specifically and on purpose left out of the standards. The standards were phrased in terms of the outcome on the resident. You can have 5011 dentists sitting around drinking coffee with their feet up on the desks and nobody gets any service. So the way to see what kind of dental service is being given is to look at the children's mouths. But the court could not act on that kind of standard of how many cavities or how many teeth had been pulled out. They wanted numbers. Suddenly the people who were drafting the standards had to include the number of staff, ratios, etc. into the standards which had been intentionally ommitted before. They also recognized that after much soul-searching and discussion, that the standards should not be the minimum standards but should be adequate stan-

dards. Although they aimed at adequate standards, it was recognized that most institutions in the country probably would not qualify at the present time to meet those standards. The court, therefore, could not use those standards as laws for the Partlow situation. So they had to adapt the standards to meet the present situation which the Partlow case raised.

I think it's an interesting and exciting idea that the F.B.I. was brought into the situation. They went around and measured the temperature of the rooms three feet from the floor. They counted the number of toilets; they counted the number of toilet seats and for those who are not familiar with institutions, it is common practice not to have toilet seats because they get broken off. They counted the square footage per bed; they counted all sorts of things. I think this is a quite interesting and novel role for the F.B.I. to play. But it's one that the courts and the other people will listen to a whole lot more than the mental retardation experts and the usual federal consultants. People don't listen to us; we've got our ax to grind. The F.B.I. is different.

Even without previously developed standards, even without previous knowledge about the condition of mental retardation, even with some limited and pessimistic ideas concerning the retarded, these people recognized that these mentally retarded were being inhumanely treated. They didn't need a professional's eye to know this. And yet the professionals have sat around for generations and allowed this to go on.

Recognizing the problems of financing, what should the Feds do? The court in Alabama is bedeviling us in every direction. I mean they can really bring pressure to provide lots of money for the residents. What will happen if we do do this? There are all kinds of state-federal relations at stake. How can you change your state plan fast enough to meet these demands? A lot of this funding comes from other than institutional funds, such as the Public Welfare Funds. If hundreds of thousands of dollars are given to that institution, could this not be an incentive to other states to lower their levels of care so that cases will be brought to court and the Feds will be brought in to solve the state's financial problems? You know Uncle Sam's got an awful lot of money but it's not budgeted for this field. That means we've got to establish many new laws and additional appropriations. That doesn't happen over night.

I would like to point out one or two special lessons. One clear lesson is that enough members of society are finally unwilling to make the retarded pay an undue share of the lack of community and institutional resources. The mentally retarded have paid a much heavier burden than have other people for inadequate social services. The public has become more aware of this. A significant number in our society are unwilling for this to continue. So if the MR system doesn't move on its own, then the courts will take over. We have profited from some of the problems and some of the successes of the civil rights fights in that kind of action.

Lesson number two: legal action is only a temporary solution. It gets the mule's attention. It shows that we must change our views of the retarded. They should not be seen as objects of pity as is so often portrayed. They should not be viewed as hopeless burdens on society, nor subhuman cattle to be penned up, but as humans to be treated with dignity and as people who have a right to the services offered to the general public. They have a right to public education, public health, public social services. We need to examine our values. Why do we respond negatively to some retarded? Why do we not always treat all of them with the kind of dignity to which they are due? And I would like to call on you to correct this situation. I want to call on you to support your state developmental disabilities planning which is a concerted, long-term, continuing effort to pull these programs together in a meaningful sense.

In this fast changing field, we must keep changing ourselves. As someone said, "Even if you are on the right track, you'll get run over if you just sit there."

So I admonish you--don't just sit there. In your discussion groups, look at what <u>you</u> do that diminishes the dignity of a retarded person; look at the policies and laws under which you operate, and move to change those that violate the rights of your charges; talk about what you should already be doing; then do it. Add your bit to the community efforts to develop those specialized services needed primarily by the retarded, but even more to open the doors of the so-called generic services to the retarded, too. Take it a little at a time and don't allow yourselves to be vanquished. "Go as far as you see. When you get there you'll see

farther." And remember Alan Paton's warning:

"To stand up for the freedom of others is one of the marks of those who are free, just as to fail to do so is one of the marks of those who are ready to be enslaved."

But first of all, be sure you understand your rights--and consequently the rights of the retarded, and then be sure you let them know their rights. Without this knowledge they are already deprived of some of their rights.

And remember, as Phillips Brooks said, "the truest help we can render an afflicted man is not to take his burden from him, but to call out his best energy, that he may be able to bear the burden." That is the essence of human dignity.

THE RIGHT NOT TO BE LABELED*

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The right to be free from a label has been approached by the court specifically in Hobson on a legal base, but not even in that famous case has the matter been specifically defined. Other continued court cases seem to but merely skirt the issue. Most have not dealt with it at all. The issue is essentially a moral one, and in an enlightened society ought to remain one of moral control rather than one necessitating judicial decision.

Labeling, if one considers the matter seriously, is an activity impregnated with all sorts of dynamics. At times society has sought labels around which people as a group could muster its aggressions. The "Hun" and the "Kraut" of the first world war; the "Jap" of the second world war; the "hippie" of the present generation are examples of this. Where does due process come into the negative labeling of the "college student," and, throughout our history, the black man. Labeling is a method by which people of the times discharge aggression from self to others, a technique through which guilt feelings are reduced in the individual and displaced on another or on a group. There are positive labels too, although almost all labels carry on a tinge of negativism. Racial, ethnic, religious, economic, and personal labels serve a significant purpose in the communication patterns of persons and groups. Dago, Polak, mackeral snapper, Wop, Nigger, Gay, egg head, Commie, pot head, junkie, fuzz, broad, chick, queer, -- each and every one of these terms is a label to which, ad infinitum, could be added a legion of others. Each serves its own end for an individual or group in society.

This right to be free from a label is more a moral problem than a legal one. The issue of the label is not necessarily that of doing away with them. The issue is making them honest and insuring that the base on which the label is used is a quality base. Police are today beginning to use the term,

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*Patricia and Henry DeYoung provided the writer with cogent and thoughtful editorial and content remarks.

fuzz, as a term of status in many communities these days. The homosexual community is bringing descriptive terms applied to it into the positive discussions of city councils and into the public market place. In the advertizing circles of Detroit, the term "wop" has only a positive connotation, because years ago Mr. W.A.P. John, "Wap" John, was a distinguished member of that media group. "I can never again negatively use the term 'wop' because of that man," said an acquaintance. "He is so genuinely fine." Labels are with us. The constitutionality of a label hinges on the honesty or dishonesty of the situation which produced the label and on what happens to a person as a result of that label. The issue is not the label per se.

We are concerned more specifically about the issue of mental retardation as a label. Mental retardation would not be a negative concept in society if ignorance, guilt feelings, conceit, and selfishness, among other things, had not made it so. If special education classes historically had been of good quality, resistance to child placement would not have been a matter of significance. If honest diagnosis and prognosis had characterized testing and placement procedures, resistance to special education would have been minimized. If religious groups had not historically placed the handicapped beyond the pale of social acceptance, we would not be fighting such a battle for the social rights of the handicapped at all levels of government now. If teacher education in special education always had been good, the birthright of the retarded or other handicapped children would not be a matter of concern today. If general educators and administrators had been given the social and moral orientation toward the equality of all persons, including those in special classes, we would never have had to face the inequalities of track systems, special classes, social promotions, or other plans which are essentially arrangements of convenience for administrators, teachers, and the general educational system. Evidence of hostility toward special education and all those things connected with it including children are to be seen and felt on all sides. Until these things are dealt with firmly and until honest equality of persons, children, and programs is conceptualized in the schools and in the communities, the negative implications of labeling of the retarded, among others, will continue as a deterent to social acclimatization of the retarded child and adult in our society.

There is no right not to be labeled. However, if society is going to label, and it will under any circumstance, then a vigilant society must

insure certain fundamentals in behalf of the individual. First, a labeling system must sort people adequately. The system of sorting or classifying must be essentially infallible. The scientific technique of society must be brought to bear on the process, and if these are lacking, society has no right to sort or must develop adequate methods before sorting continues. The stipulated agreement in the Diana case included an instruction to develop intelligence tests to be used with non-English-speaking children which would be conceptualized and be standardized, not on a white middle class culture, but on achievement norms of the culture of peers. The court here facilitated the invention of new reliable techniques. Within the capacity of the science, sorting must be infallible. An example of infallibility which must be applied in the grouping of children for instruction is seen in another field, namely, the certification of athletes in Olympic competition. An analysis of saliva and hair structure characteristics is applied to determine whether an individual will compete among a group of men or a group of women. Grouping here is accepted insofar as there is an appropriate base for grouping. The technique of grouping is accepted as honest, objective and capable of reliable replication in all situations. The more subtle issues of sorting in terms of intelligence must be approached with the same scientific detachment, and instruments which are ethical, reliable, and appropriate to the socio-economic, language, and cultural characteristics of the individual are required and must be created.

There is nothing inherently wrong with the concept of sorting per se. In educational circles the concept of meeting individual needs has long been recognized. Recognized too, but not so often verbalized, is the fundamental fact that for the best teachers there is a range in individual needs beyond which one cannot go with advantage to the child. It is not the fact of sorting per se which is always objectionable, but the fact that when sorting is accomplished and the special needs of the retarded are identified, these children are submitted to educational programs which often are inferior. The second fundamental principle then is that a program of sorting by intelligence cannot be permitted to result in injury to the child. It cannot adversely affect the individual. The courts are aware of this, and if there is a possibility of adversely affecting the child after a legitimate label is given, schools will rightfully be brought into the courts to defend their practices. Mental retardation is a label which can have positive connotations

if the program which the child experiences is recognized by the community as being quality and beyond any negative criticism. The negative label comes in direct relation to the degree of mediocrity characteristic of most of special education and the result of the rejection of special education by general education at all levels. Any system which adversely affects a child denies him equal protection, and general educators have caused special educators to do this for a century or more in the U.S.

Hobson directs our attention to a third factor. Grouping cannot result in an over-representation of certain socio-economic or cultural categories. Such over-representation means that the techniques of grouping are indeed highly suspect. It follows that the educational program cannot possibly meet the needs of children so grouped because faulty techniques have sorted children into educational programs based on reasons having little to do with educational programs. Disharmony exists between the child and a program intended for another purpose and the negative aspects of labeling are accentuated. Minority over-representation in special classes focuses the spotlight on poor diagnosis, inappropriate programming as the result of misplacement, and dishonest labeling.

Over-representation again is not inherently determined. Hobson recognizes the validity of over-representation in certain educational classes if there are compelling reasons and if these can be adequately defined. For example, adequate diagnosis placing Chicano children together temporarily for English language development would not be challenged nor would negative labeling take place.

Sorting then must be for the benefit of the child and the wisdom of such sorting must be subject to proof. Heterogeneous grouping may be as educationally and administratively immoral as any other technique. It is not the easy solution. If sorting is done, it must be done for the benefit of the child. The issue is not the right to be free from a label, it is the right to be free from the imposition of a label rife with negatives. The issue is philosophic and moral; when people are forced into making it a legal issue, it is a sad commentary on us.

In a democratic society a system is required so that the individual is not lost. Special education, founded upon the best of a science in diagnosis and prognosis, in teaching, in materials, and in curriculum, can not only

prevent the individual from being lost. It can also elevate the retarded child, among others, to the height of his capacity. In doing so pride of general accomplishment is experienced by the child and his family, and the label he carries has essentially positive connotations and itself can become motivational.

We have emphasized the moral issue of the problem of labels. If we have to rely on the courts to enforce our honesty, it will probably never happen, because there is no enforcing agent in society or specifically in the schools in this area short of a police-state concept. On this matter the court can sensitize, it cannot enforce. The court has much power, but it does not have the power to force men to think honestly. Only the society which created the courts has this power. As men's minds see clearer the rationality of honest dealings with one another, labeling as a negative concept will be replaced by labeling of appropriately honest dimensions.

THE RIGHT TO FINANCIAL ASSISTANCE

Mrs. Mary I. Wagner
Parent and Director of
Community Living Centers, Inc.
Farmington, Michigan

With the definition of assistance in mind that we are helping, aiding, and assisting in finances, we are fulfilling a desirous accomplishment. We all need the feeling of independence, of self-esteem, of being important to someone, of paying our own way, and of supporting ourselves.

We all know the good, good feeling of cashing a paycheck and patting a wallet with cash in it. If we can remember back far enough even the good feeling of having a nickel, dime or even a big quarter in a fist--our allowance--what a good feeling.

We cannot or must not rob our retardates of that same feeling of accomplishment, of having earned something be it a quarter, a dollar, or fifty dollars. When we say a right to financial assistance, let us keep upmost in our minds the real meaning of assistance and then go on to the rights.

This is a quote by Thomas Jefferson which comes from an inscription in the Jefferson Memorial in Washington, D.C., hopefully inscribed in our thinking:

> "Freedom is the right to choose, the right to create for oneself the alternatives of choice. Without the possibility of choice and the exercise of freedom, a man is not a man, but a member, an instrument, a thing."--Thomas Jefferson

By our laws the disabled are granted assistance and we as counsellors, social workers, directors, and parents have the obligation to make sure the necessary assistance is provided to them. In our social service statute, a declaration was made in July, 1970, that a person at the age of 21 was a family in his own right. He was not the responsibility of a parent, nor was he responsible for his parents. This opened the door to many of our retardates--the door of independence. With assistance and supervision they could leave home, as their peers left to marry or go to college at age 21, 22 or 25 and become an independent citizen. They could receive money in their own name and pay their own room and board. Remember that feeling of your first dime or nickel ? Think of the good, good feeling some of these people experience when, for the first time at age 20, 30 or even 40, they

have their first paycheck and pay their own way.

With the declaration of July, 1970, that all persons over 21 were a family in their own right and did not have to consider family or parental finances, application was made for several adults involved in community living. All were accepted and began receiving assistance to supplement their wage earnings.

One young man who was accepted needed only $50.00 per month. After a few months he received notice that his aid was terminated because he was steadily employed. The local social service office contacted said this was a determination from the medical examiner department.

The following quote is from the hearing memorandum:

> "After reviewing the medical and social material on the above captioned client, with careful consideration of this client's living arrangement and employment history, the decision of the State Review Team is that this client is not permanently and totally disabled as defined. In general, 'permanently and totally disabled' means that the individual has some permanent physical or mental impairment, disease, or loss that substantially precludes him from engaging in useful occupations within his competence. In Mr. Doe's case, the fact that he is employed full-time in a regular and predictable manner disqualifies him from being considered disabled. . ."

The medical examiner made the statement that were this person not working steadily, he could receive full benefits. This would have taken away everything he and his advocates had worked for -- independence, even the partial self-esteem so very much needed, and the ability to live up to his full potential. A hearing was requested and granted. Legal aid was permitted, so a brief was very thoroughly prepared and presented. The Social Service Department, realizing the true meaning of group living and the need for just minimal supervision by so many, made a declaration. A person even though he be steadily employed, but needed the help of another for his daily care and needs, was eligible for assistance.

The following is from the hearing memorandum:

Conclusions of law:

> Section 400.25a of the Social Welfare Act being Michigan Statutes Annotated 16.425 (1) states in part that:
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> "Aid to the permanently and totally disabled shall be provided through the county department of social welfare, in accordance with rules and regulations of the state department, to any needy individual who is at least 18 years of age and who is

permanently and totally disabled. . . The director may further define by rule the words 'permanently and totally disabled'."

The above provision, of course, sets out the legislative mandate empowering the Department of Social Services to establish the Aid to the Disabled Program. This department has complied with the legislative mandate contained in the above statute by defining the terms 'permanently and totally disabled.' Administrative Rule 400.10 as promulgated by this department contains in paragraph 7 a definitive definition of the term 'permanently and totally disabled.' That section states in entirety that:

"(7) In aid to the disabled, a person will be considered to be permanently and totally disabled if it has been established by medical and other evidence: a. That he has a physical or mental impairment or a combination of impairments which cannot be corrected within the foreseeable future, and b. That by reason of such impairment(s) he is unable without the help of another person to carry on the minimum activities essential to daily living as determined by the state social services director."

It may therefore be seen that in order to qualify for AD assistance an individual must meet two standards. He must show that he has a combination of impairments which would exist for such a time as to render him permanently disabled. Further, these impairments must be of such a nature to render him totally disabled by either (1) precluding him from engaging in useful occupations, or (2) making him dependent upon the care of another individual to carry on the activities of daily living. Your Referee therefore concludes that the argument as advanced by the petitioner and noted above is correct. The individual who meets either one of the above quoted standards of totality will be considered eligible for aid to the disabled regardless of whether or not he meets the other above quoted standard.

The force of the petitioner's argument is magnified by language contained in Public Assistance Manual Item 295. The definitions contained in the introduction to Item 295 include a definition of the word totally or totality. Public Assistance Manual states that:

"Totally, or totality, refers to the extent the impairment results in restricted activity, either in the person being substantially precluded from engaging in a useful occupation for which he is otherwise qualified or in need of the help of another person to carry on the minimum activities essential to daily living..."

Public Assistance Manual Item 292.2(2) B. state that:

"...Determination of totality must be based on the need for help of another person or on inability to engage in useful occupations."

Further, Public Assistance Manual Item 295.5, B.2 states that:

"Eligibility exists on a totality basis if the person has a permanent impairment that causes him to require the help of another person in the minimum essentials of daily living. The need for help from another person is to be determined by evaluating that which is necessary to maintain the client's life, health, or safety in his present living plan. A client whose impairment results in need for regular housekeeping, nursing, or protective care from another person (not necessarily full-time care) meets this requirement."

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"Housekeeping includes the basic tasks of maintaining the normal operation of the client's household, such as cleaning, cooking, maintenance of heat, washing and ironing, shopping, and related activities."

It is therefore clear to your Referee from all of the above quoted information, and Administrative Rule 400.10(7) that there are indeed two separate tests of eligibility for aid to the disabled. It is your Referee's opinion based upon all of the facts presented in the foregoing findings of fact that this petitioner is dependent upon other people to carry out the minimum activities of daily living. Your Referee therefore concludes that this petitioner is totally and permanently disabled as defined within Administrative Rule 400.10(7) and consequently the AD grant of this petitioner should not have been closed.

Recommendation:

Based upon the foregoing findings of fact and conclusions of law, it is the opinion of your Referee that the action of the Oakland County Department of Social Services in terminating the AD grant of John Doe should be reversed. Your Referee further finds that Mr. Doe should be reimbursed for the period his grant was closed by the county, less any amounts he may have received on general assistance.

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We have had the wonderful experience of seeing a young man receive his first paycheck at age 34, pay income tax and brag about it, get a rebate check and celebrate, and is proud to death of being a dishwasher (an indepensible dishwasher) in a nursing home for two and a half years.

We know the right to financial assistance exists. It is the duty of everyone involved in this exodus from the institutions to make sure that

our people are properly placed, properly financed, and happy citizens. We must be continually vigilant and not for a minute let up that vigilance for fear one person might be lonesome, fearful of the unknown, not have a supporting hand, and not be successful according to his potential. That potential is our job to seek, to work with, to know how much support so as not to smother, and to evaluate so as to know when to let go.

May God grant us all wisdom to do this job wisely so that this exodus will not be a catastrophe.

THE RIGHT TO EDUCATION

Mr. Lynwood Beekman
Attorney
Lansing, Michigan

The right of a handicapped child to an education - leave out the word "handicapped" and everyone would take such a fundamental right for granted. But, that's the problem - we in the State of Michigan, through our legislature and administrators of our educational system, have with respect to education, left the handicapped child sitting on the sideline, or more realistically, sitting at home.

Under Michigan's Act 220, a study was conducted among local boards of education regarding the need for special education programs and services. The results of that study indicated that upwards of 10,000 handicapped children were not receiving any services whatsoever. In addition, upwards of 36,000 children were awaiting diagnosis, and upwards of 60,000 were awaiting placement. With respect to these latter two categories, it should be noted that many of them were receiving classroom services at the time of the study, and therefore, the numbers reflect many who were only in need of supportive services.

It must be pointed out that the result of this study is merely an estimate of the problem. First, the results were based upon reports from local school districts who made varying interpretations regarding classifications and varying degrees of effort in attempts to obtain accurate statistics. Second, the results are approximations because of the present testing and classification methods being implemented. Third, the figures do not include persons who were in inadequate or token programs. Finally, the study was conducted a few years ago and therefore the figures are not current.

But regardless of the exact numbers which we are talking about, one thing is certain. We do have a problem - there is no doubt about it. The question is only the magnitude of the problem and with the number of handicapped children being in the thousands, the problem is of tragic proportions.

Legally, I really do not believe there is any question that handicapped persons have the constitutional right to an education. The due process and equal protection clauses of the Constitution of the United States of America

guarantee that neither this state, nor any other state, which has granted public educational opportunities shall deny such educational opportunities to certain persons on the basis of laws which establish classifications which are arbitrary, capricious or irrational.

One would think that under such a standard, the denial of an education to the handicapped as a class would be, not only arbitrary, but capricious and irrational, as well.

Looking at the law of the State of Michigan, the Michigan Constitution of 1963, Article VIII, Section 2, reads in pertinent part:

> "The legislature shall maintain and support a system of free public elementary and secondary education schools as defined by Law." (It is important to note the words "as defined by law.") "Every school district shall provide for the education of its pupils without discrimination as to religion, creed, race or national origin."

Section 8 of this Article further provides that services for the handicapped shall be fostered and supported.

I submit that it is terribly interesting to note that in Michigan's Constitution, if you are black, or if you are Jewish, or if you are Polish, or very soon, if you are a female, you cannot be discriminated against in terms of educational opportunity. But, if you just happen to be handicapped in the State of Michigan, you can and very frequently will be denied an educational opportunity. The reason for this gross inequity is that the educational system established under the Constitution "as defined by law" provides that educational programs for the handicapped are permissive, not mandatory. In other words, whether handicapped persons receive any education or training is left to the discretion of the local board of education.

I was recently involved in the drafting and passage of Act 198 of the Public Acts of 1971, generally referred to as the "mandatory special education act." While this act will become effective on July 1, 1972, the mandatory nature of this act will not become effective until July 1, 1973. Basically, the act attempts to guarantee the right of all handicapped children to an education, that is, education and training which is described in the act as sufficient to develop the handicapped person's "maximum potential." In addition, the act provides a delivery system including planning at various levels, identification and evaluation procedures, and enforcement procedures.

On May 25, 1972, a suit was commenced in federal court in Detroit. As I understand the relief being sought in that suit, it is to gain immediate implementation of Act 198, or whatever educational programs and services are constitutionally required, compensatory programs for those handicapped individuals who have previously been deprived of educational opportunities and due process hearing procedures in connection with the initial placement and later re-assignment of handicapped children.

While I believe the mandatory special education act has, from a legal standpoint, sufficiently clarified and guaranteed the right of the handicapped to an education, I am confident the federal court will, when it renders its judgment, further establish this right.

The implications of education for handicapped persons while long obvious to many in the special education field has now, with the passage of Act 198, to some degree been recognized by Michigan's legislature. In short, education is more that the three "R's" or academics - to prepare certain persons for life, to make their lives meaningful as individuals and beneficial to society as a whole, they must be offered specialized education and training "to develop their maximum potential" - in other words, a special education.

Many might think a presentation regarding the rights of the handicapped to an education could very well end at this point. I have pointed out the problem and conceded that by Act 198 and possibly the federal law suit presently in progress, the right to such an education on behalf of the handicapped has been established. But, the fact that certain people might think this, points out the real problem in securing an education for the handicapped. Most of those involved in attempting to gain this right, such as parents of the handicapped, leaders of special education organizations, university educators, and attorneys, as well, assume that constitutional and statutory guarantees, statutory and regulatory guidelines and enforcement measures and court orders will guarantee and obtain for the handicapped the education and training which they need. In making this assumption, I submit such persons have made a tragic error.

Education is only as good as the boards of education in charge of the school programs, as the administrators who plan, develop and administer the programs, as the teachers and related staff who attempt to carry out such

programs by their direct contact with the handicapped. These are the key ingredients of an education, and no constitution, no statute, no regulation or court order can guarantee or insure that the proper people are in these positions or that such persons, if proper, are performing their appropriate tasks and responsibilities correctly and to the utmost. I believe it is here that you as professionals and as parents can, by your advocacy, through inquiry and participation, make the handicapped's right to an education meaningful. Unfortunately, today it is fashionable to look to the law and especially to the courts for relief from our problems, expecting laws and the courts to solve those problems with little effort on our part. We must get out and start getting involved with these problems ourselves in order to see that the purpose and intent of the laws and court orders are carried out.

I would offer certain suggestions to each of you on how you can better insure the handicapped's right to an education. These suggestions will be primarily tied into the delivery system as established and set down in Act 198. However, I think these suggestions could be utilized in other states where the constitutional or statutory right of a handicapped person to an education has been established. Under our act here in Michigan, we have basically three agencies which are involved in the administration and development of programs. As parents and professionals, the operation of each agency presents an opportunity for you to be an advocate.

First are the local boards of education. With respect to their composition, you can strive to elect persons who are dedicated and interested in the problems of the handicapped. Further, either as individuals or as part of groups such as PTA's or special education organizations, you can participate on board-appointed committees concerning the planning of special education programs, the curriculum of such programs, the selection of staff, a study of equipment needs or possibly transportation problems.

As a parent of a handicapped child, you havean unique opportunity to become extensively involved in evaluation procedures, most specifically with respect to your own child. Under Act 198, it is envisioned that a parent would become involved in the evaluation of his child from the outset. In the past, many educators have felt that parental involvement in the evaluation of a child was unwise. However, it is now believed that such

involvement will benefit the education of the child by obtaining the full commitment of the parent to the educational program finally agreed upon.

Last, in many of these programs offered by local boards of education, there are opportunities for you, either as parents or professionals, to volunteer your services. In the Lansing area, for example, I know they have several volunteers who actively participate and make substantial contributions to the programs being offered.

Turning to the second agency involved in the administration of special education programs, it is the intermediate board of education, or what used to be referred to as county boards of education. Under the mandatory special education act, intermediate boards of education are given certain duties to oversee the operation of special education programs as they are operated by local school boards. However, under some circumstances, intermediate school districts may operate programs and services. In such instances, all of those items mentioned above in connection with programs operated by local boards of education would be applicable to intermediate boards of education, and you, either as parents or professionals, could participate in the operation of such programs at the intermediate school district level.

Whether the intermediate board operates special education programs or not, there are other opportunities for you to participate. For instance, already established by law are advisory committees, composed partly of parents. In addition, under the mandatory special education act, there is a requirement that intermediate school districts formulate plans for the delivery of special education programs and services throughout their intermediate school district areas. These plans will be formulated in consultation with local school districts, and it is contemplated that intermediate school districts will seek and solicit the participation of parents of the handicapped and their views in the formulation of these plans.

Finally, the mandatory special education act establishes certain reporting procedures. First, with respect to handicapped children who are not being served at all or who are being served inadequately, as a parent or a professional, you may file a report with the intermediate school district bringing to their attention a child who is possibly being deprived of a proper educational opportunity. Second, the act provides for the

reporting of local school districts who fail to provide a particular special education program or service, or whose operation of a particular program or service is contrary to appropriate statutes or regulations. It is hoped that such reporting procedures will give greater assurance that all handicapped children are being provided the appropriate special education program or service as required by law.

The third agency to be involved in the administration of these programs is the State Board of Education. Again, inasmuch as the members of this State Board of Education are elected, you, either individually or as a member of a group, have the opportunity to see that the members of said board are aware of the problems of the handicapped.

For but a very few of you, the special education advisory committee, appointed by the State Board of Education, presents an opportunity for your participation. The committee is composed of nine members, at least two of which are parents. Other members of the committee are professionals in various fields.

One of the greater opportunities for your active participation in the formulation of the law and regulations which will govern the operation of special education programs and services in this state will be at the public hearings to be held by the State Board of Education pursuant to the mandatory special education act. These public hearings will be in connection with the State Board of Education's promulgation of various regulations covering such matters as the definition of "handicapped person", the criteria for admittance to particular special education programs, evaluation and testing procedures, reporting procedures, recording procedures, the qualifications for teachers and related staff, curriculum and equipment guidelines, and a host of other matters. The details and regulatory guidelines for the operation of all special education programs and services will be established by the State Board of Education, and at these public hearings, you will have a perfect opportunity to make your views known.

Finally, the State Board of Education, or more specifically, the Director of Special Education with the Department of Education, should be your last resort in terms of trying to obtain relief with respect to program irregularities. In the event your reports to local school district or intermediate school districts fall on deaf ears, contact should be made

with the office of the Director of Special Education in Lansing. Preferably, a letter should be sent indicating exactly what the program is, who you have previously contacted, and the nature of the inadequate responses you have received. Administrators at the state level are gearing up to be ready to deal with potential problems in implementing the mandatory special education act, so do not hesitate to call on them if the need arises.

In addition to the opportunities presented in the connection with the operation of the three types of agencies mentioned above, the Michigan legislature deserves mention. It is the body which controls the financing of these special education programs and services. Accordingly, attention should be paid to see that the legislator to be elected from your district is aware of the problems of the handicapped. Between elections, you should continue, either individually or through group action, to remind legislators of the educational problems of the handicapped.

Now, if your efforts at all these levels fail, and you have still not effectively forced a local or intermediate board of education to live up to its statutory or court ordered obligations to furnish the handicapped in your area an education, a court's assistance must be sought requesting very specific action on the part of a specific administrator with respect to a specific child or situation. Such court assistance is a last resort and then only a temporary remedy. The real remedy lies with you who, by your advocacy, should strive to correct the problem at its source whether it be within the local board of education, its administrators or the teaching staff.

In closing, I want to stress again that it is easy, when speaking of the right to an education, to talk in terms of constitutional guarantees, statutory guarantees, and court orders. Avoid the temptation. You must get down to the brass tacks of education. Even assuming such guarantees are all there, you are still not going to assure the right unless you start looking at the basic relationships that make up education - board of education and administrator, administrator and teacher, teacher and child. The effectiveness of these various relationships will determine whether your school district will provide a meaningful special education program. You cannot sit back and rely upon the mandatory special educa-

tion act or a court order to bring education to the handicapped children in your area. If you do, I submit you are making a very sad mistake. Unless you become advocates of the right of the handicapped to an education, I firmly believe you are going to find the right, rather than being a reality, will merely be the hollow words of the mandatory special education act or some court's order.

THE RIGHT TO COMMUNITY SERVICES

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Someone said to me "Well what is the President's committee on mental retardation?" Well, it was established by executive order in 1967 after a very extensive study that was started under John Kennedy's presidency. It is now a panel of 25 members, one-third of them made up of parents of retarded children, one-third made up of people who are professionally involved in working with or working for the mentally retarded and then those who have a deep and abiding concern for the retarded. It is a fascinating committee. Believe me, this is one of the hardest working committees I have ever been on. You are on call 24 hours a day to go in any direction to help in any way you can. We've been involved in many legal cases, directly or indirectly. We have been in consultation in many areas where deprivations have become so evident that people have come to us and said "Will you identify this and help us to resolve it?" I've been a participant in several national conferences on juvenile delinquincy and the naive offender, which is really the retarded offender, he may be a juvenile delinquint or an adult criminel. But he's also retarded. I also participated in the National Conference on Adult Corrections and everything that's being said this morning has been said over and over again - the rights of the individual and the right to certain services. We must be concerned about the fact that most of these people have been deprived of their basic rights which we as people have just accepted as part of our heritage. It's too bad that we cannot coordinate this tremendous thrust, involving thousands of people who are working and concerned about the violation of human rights--whether it is for the mentally retarded or any other group who is effected. To guarantee these rights that we are talking about (especially when we get into the community services which is really a catch-all for every type of service) we're going to have to have federal legislation. We're going to have to have state legislation. And we've got to have, more importantly, community implementation. There may be laws within your community which are going to have to be challenged and in some instances again we are going to have to have more legal intervention. But more importantly we have to consider the fact that everything must be not just

adequate but better than and more than.

The engraving on the beautiful building that houses the United States Supreme Court in Washington states simply, "Equal Justice Under Law." But three centuries of great changes of law, have done nothing for the mentally retarded. Actually the idea of rights for the mantally retarded is new. A century or less ago, most people, even many of the learned professions, and the parents and relatives looked upon the retarded as hopelessly incapable, often dangerous, almost a subhuman creature, and were not thought of as having legally enforceable rights. "Indeed, when the term 'rights' was used in relation to the mentally retarded, the reference was usually to the prerogative accorded to relatives and creditors to obtain appointment of a guardian or conservator to prevent waste or destruction of any property that might come into the possession of the retardate, or to the right of society to protect itself against retardates derelictions and unwanted offspring, by confining him and sterilizing him...." We know that the retardate is not hopeless, but many were surprised and scoffed at the declaration of general and specific rights of the mentally retarded published by the international league of societies for the mentally retarded three years ago. It stated unequivically that: the mentally retarded person had the same rights as other citizens of the same country and same age," and concluded with "above all the mentally retarded person has the right to respect. Right to respect, personal dignity, acceptance as an equal member of society with freedom from discrimination, and the right of being identified as a human being--a person." The acceptance of these two, identification as a human being, and a human being with equal rights form the basis, established the foundation of success or failure in the availability and effectiveness of community services. The establishment of this foundation is the tough problem and the most difficult problem to crack.

The public lacks understanding and flounders in a sea of misconceptions. The public is not interested, the public is apathetic and in too many instances only arousing from this lethargy if their home, their neighborhood, their pocketbooks are threatened. Why community services? Why not the state? Why not Washington? I stress the community, because this is where the retardate is or should be and where services must be available. What are the community services to which the mentally retarded have rights?

1. Right to appropriate physical and mental health care
2. Right to adequate housing
3. Right to adequate food and nutritional care
4. Right to an education
5. Right to enjoy the community through intellectual, cultural, and recreational activities
6. Right to social development and meaningful relationships with others
7. Right to be trained and have a job to earn an adequate living, and to receive equal pay for equal work
8. Right to privacy
9. Right to have these needs met, adequately, not as tokenism or not crisis intervention

The guarantee of these rights go beyond merely passing legislation and then forgetting the funding. The implementation of these rights needs to be well planned and developed in an ongoing base. I would like to talk more specifically about certain specific rights: The right to physical and mental health care. This means there must be:

1. Increased training of professionals and para professionals to assist in early identification.
2. Special diets, drugs, surgery, therapy, and home nursing care available.
3. Early screening for identification of learning disabilities.
4. Psychiatric and psychological services available.

The right to adequate housing means that:

1. Poverty must be confronted. Poverty supports and aggrevates mental retardation--poor housing is a part of the problem.
2. Lead poisening is a major cause of mental retardation and is allowed to reach near epedemic proportions before anything is done. How many houses in your community are quilty? It is the communities responsibility to see that this major threat is eleminated not just painted over.
3. Rats, bugs, dirt, depressing environment effects a child's development. It's amazing how many children are able to survive--but it's just survival.

The right to adequate food and the right to good nutrition:

1. The malevolent partnership between low income and intellectual deficiency is well documented. It is estimated that 75% or more of persons identified as retarded come from families who often have been living at bare subsistent levels for several generations.
2. Maternal malnutrition can impede brain cell development in an unborn child. Poor diet during infancy can also damage the brain. Even if the brain develops normally, growth of the intellect may be stunted. (50% to 75% of our juvenile delinquents are functionally retarded.)

The right to enjoy community programs:

1. Retarded infants should be provided with residential nurseries and child welfare services when needed
2. Toddlers should have adequate foster care, nurseries, or trained baby sitters.
3. Children should have short stay homes, boarding schools available to them.
4. Youth should be provided half way houses, group homes, foster homes when needed.
5. Adults should be assured of long term residential care, or group homes if required.
6. Older adults should have boarding homes or group homes available.

The right to social development means that retarded infants have the right to be loved, fondeled, talked to. As they develop they should have the following programs available:

1. To receive home training in an enriched environment.
2. Involvement in day camps, residential camps, youth groups, social clubs.
3. Sex education, marriage counseling and instruction in family care.
4. Recreation, gyms, pools, bowling,dancing, rap sessions.
5. Religious education.
6. Right to needed transportation.

The right to employment. Retarded children grow up into retarded adults, who must meet all the challenges of "normal" adulthood. The need to get a job and to keep it. They need to care for themselves and their families.

Many retarded will never be financially secure or intellectually competent. For these people assistance will be a life long necessity. Service should be compassionate and ungrudgingly rendered, but it should be accompanied by increasing effort to seek out and maximize individual potential.

Unemployability is determined more by society's economic needs, than by individual shortcomings. During World War II, large numbers of supposedly unemployable people were recruited into the labor force and civilian unemployment was reduced to about 1%. So called unemployable people who were hired, for the most part, performed their jobs well.

Much mental retardation could be alleviated by positive, significant and lasting improvement in over all standards of living, job training and continued employment is indespensable. In reviewing the rights of the retardate, it is clear that only with the development of a comprehensive, realistic plan of action for and by the community as a whole, can we begin to deliver services effectively.

I prefaced my remarks with a complaint about public apathy. To attain our objectives, there is required an intensive public education program that means that every type of public information must be brought to bear in helping to develop understanding and honest acceptance of our goal. To persuade and prepare the community to assist those individuals who will need "shelter" in all forms of daily living. Each of us has a major responsibility--we must stimulate awareness and acceptance or our boys, girls, young men and women, and the older citizens who are retarded. We must prepare the retarded to come back into the community, to make that transition from closed isolation to open involvement. We can pass laws, but laws have to be implemented and unless you and I stay on the firing line we are going to fail in our efforts, and regression will set in. Because hope of those whom we represent will

But never underestimate the human capacity for change. People can change, society can change--can change attitudes and disconceptions--and these changes comes the new direction of human services. The President's committee is involved one...in every area and we stand ready to serve you and your charge.

THE RIGHT TO TREATMENT IN STATE INSTITUTIONS

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The conditions under which the mentally retarded exist in our state residential institutions have been documented repeatedly in the literature (Baumeister, 1970; Butterfield, 1969; Blatt, 1969; Nirje, 1969; President's Committee on Mental Retardation, 1967, 1968). Some of the problems illustrative of conditions in residential institutions for the retarded need only be listed once again without elaboration:

1. Inadequate staff-resident ratios.
2. A penal-custodial atmosphere in which the ward attendant has been priviledged to play the role of jailer.
3. Minimal training, experience, and qualifications of the professional staff.
4. Domination of treatment programs by medically-oriented concepts of disease.
5. Minimal salary scales for professionals, supervisors, and ward-level personnel.
6. Administrative procedures which deemphasize treatment rights as a priority.
7. Fiscal appropriations which are determined by economic and political forces independent of the needs of residents.

Does the retarded resident have a right to improved care and treatment? On April 13, 1972, the United States District Court in Alabama ruled as follows in Wyatt vs. Stickney:

> Because the only constitutional justification for civilly committing a mental retardate, therefore, is habilitation, it follows ineluctably that once committed such a person is possessed of an inviolable constitutional right to habilitation. (Wyatt vs. Stickney, p. 4)

The aspects of the ruling critical to this paper are the requirements for a human rights committee and the establishment of minimum constitutional standards for adequate habilitation of the mentally retarded. The specifications

for these minimal standards essentially provide a form of legal accountability. Although we can view the court decision in Wyatt vs. Stickney with a feeling of security regarding a precedent for the legal status of habilitation, a feeling of pessimism must pervade our hopes for the retarded when this decision is placed in the context of the 1954 school segregation ruling and our country's reluctance to accept it.

Even more importantly, the pressure for community placement may indeed provide a rationale for restricting or terminating services in the residential institutions despite legal rulings. How then do we provide a system to insure the human as well as constitutional rights to habilitation for the mentally retarded? From a different perspective, who needs the advocates in the state systems?

Obviously, the residents should be the primary recipients of legal and non-legal advocates. The post-trial memorandum by the amici curiae in Wyatt vs. Stickney suggested a legal advocacy office in the institutions to insure the protection of the legal rights of the residents. Unfortunately, that recommendation was not retained in the final decision. Each state institution should have on its premises a lawyer responsible to and paid by the Attorney General's office whose sole purpose will be to provide legal counsel and review for the residents and their guardians or parents. This individual should not be accountable to nor available to the superintendent for legal services. Furthermore, a mental retardation specialist from any discipline should be appointed as a professional services advocate by the Governor's office and accountable directly to the Governor. His responsibility will be in the area of professional services in that he will be responsible for monitoring all treatment programs and collating all data on the success of these plans. As with the legal advocate, he will be independent of the superintendent.

The next level of advocacy for the residents should be the human rights committee composed of parents of residents, professionals from outside the mental retardation system of the state, and appointees from the general public. They should be accountable to the director of the state system regarding the adequacy of care and the protection of the human rights of the residents. If either the advocates or the committee are accountable to the superintendent, a form of tokenism will ultimately permeate their functioning and reduce their ability to effect change.

There are, however, other procedures which should be implemented in order to increase the efficacy of the advocates. All professional staff positions should be removed from the civil service status they now enjoy and be assigned to the budget of the state department of mental health or hygiene which will have the ultimate responsibility for the performance of these individuals. All professional staffs should be grouped under departments within the institutions with an administrative director who is responsible directly to the superintendent for the professional conduct of the discipline. Decisions regarding the competency of the professional staff must rest within the system and not in the procedures of a civil service system;otherwise accountability becomes a matter of tenure and not performance. All reports on performance submitted to the superintendent or the state system must also be filed with the professional advocate.

The professional programs within the institutions must be comprehensive and complete regardless of the status of community placement programs. Prior to community placement, the state system should insure in writing that all services needed by the former resident are present at the appropriate professional level and available in terms of distance and finances to the retarded. The residents who remain in the institution should have equal services available to them. The stated intent to utilize community services for the institutionalized retarded must be evaluated in terms of availability and adequacy of services. The assumption that the community will serve the institution has not been borne out in the past and there is no reason to believe that the future will see significant changes. When one considers the fact that most institutions are tucked away in rural settings where services are rarely available to the local citizens, the proposal to use the community to serve the institution becomes even more questionable.

The role and status of the disciplines within the state institutions must be carefully evaluated. All disciplines should be viewed as being of equal status in the decision-making process regarding treatment programs for the retarded. It has become popular among the non-medical professions to castigate and deprecate medicine for its role in the history of mental retardation. Obviously, the abuses of the past were significant. However, the behaviorists have yet to demonstrate that their "model" which will replace the "medical model" is more efficient or appropriate for the mentally retarded. Indeed, as a speech pathologist, I become quite concerned when I read or hear reports by

psychologists or social workers which recommend or deny speech and hearing services. I have had the recent experience of conversing with a representative from another behavioral discipline in an administrative position who has decided that his institution does not need a staff audiologist even though the institution was responsible for the deaf-retarded in the state. Whether it is a physician or a non-physician who is making the decision outside of his professional training, the injustice to the retarded remains the same.

There is another group, however, who needs an advocate. And that group is the ward attendant. The present drive to make the ward attendant responsible for professional treatment of the resident is untenable, unfair, and is being forced upon the attendant and the resident without justification. A clear distinction must be made between in-service training for the attendant in order to improve his skills in that role and the development of a separate category of support personnel who will work under the direct and frequent supervision of the professional staff. To expect that the ward attendant shall be ultimately responsible and accountable for the development of the resident is a violation of the conditions under which attendants are employed. However, if attendants are assigned such tasks, the time devoted to such professional activities should be determined and salary adjustments at the level of the highest-paid professional in the institution responsible for that task should be made. The professional advocate mentioned earlier should monitor this issue as the evaluation of programs is being performed and reported to the Governor.

The quality of professional services in state institutions can be attributed to several factors including salaries, location of the institution, professional isolationism, and the tremendous degree of frustration inherent in serving large numbers of difficult cases. However, there is an even more important reason in my judgment. University training programs have very effectively conditioned professionals not to work with the retarded or to expect only minimal success with them. One reason for the lack of speech and hearing services for the retarded is because the literature, research, and training in communication disorders have tended to prejudge the retarded as being incapable of making progress. Even more striking are the writings of researchers who have neither evaluated nor conducted clinical programs but are willing to make programmatic decisions on the basis of some theory. Parent groups must begin to apply the same degree of pressure on universities

as they did upon educational and governmental bodies during the 1950's and 1960's. Furthermore, the state departments of mental health must start to provide training grants and/or programs for their staff members who lack training in mental retardation.

The suggestions raised in this paper are only some of the procedures which should facilitate the improvement of services to the retarded. There are others, some of which can be found in the Wyatt vs. Stickney decisions, others in the professional literature. The obvious concerns about society's attitudes and the past conduct of state legislatures and administrators were not worth the effort of repetition. Essentially, this paper attempted to focus upon providing a political, economic, and professional support for treatment to the retarded. They are expensive recommendations but so are the present systems and their abuses. We need long-term choices and not short-term political gains.

THE RIGHT TO MARRY AND THE RIGHT OF CHOICE REGARDING STERILIZATION

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Several kinds of state laws currently limit the freedom of those labelled "mentally retarded" to engage in sexual relations, to marry, and to rear children. In a significant number of states persons found "mentally retarded" can be compulsorily sterilized, can be denied marriage licenses, or can lose custody of their children. In recent decades these laws apparently have been only rarely invoked. This may be because the most likely targets for these laws are those "mental retardates" whom we have placed and forgotten in long-term custodial institutions. Greater efforts are now under way to avoid institutionalization of the retarded. This new emphasis demands that we scrutinize the existing state laws which threaten to curtail the freedoms that community placement for the retarded may be intended to assure.

In 1966, twenty-three states had statutes providing for compulsory sterilization of mental retardates. In eight of these, the statutes permitted sterilization whether or not the person found retarded had been institutionalized on that ground. For the rest, sterilization laws applied only to institutionalized mental retardates. As a general matter, however, these laws are today rarely applied. It may be that little necessity for their application is seen, on the ground that life-long confinement in a single-sex unit of a residential unit is an even more effective means of constricting heterosexual relations than sterilization.

In practice, the prime targets for compulsory sterilization appear to be those retardates who are being released from institutions. Some state laws have in fact explicitly required sterilization as a condition for release. Even where there is no state law authorizing compulsory sterilization, it apparently is often imposed as a condition for institutional release, usually with the proviso that sterilization is "voluntarily accepted." (Similarly, state laws removing custody of children from the "mentally deficient" or prohibiting the retarded from marrying--variously identified in state marriage licensing laws as "mental deficients," "idiots," "imbeciles," "feebleminded" and the like--are most likely to be applied to those with prior histories of institutionalization.) There are no reliable statistics

available on the frequency of application of any of these laws. The most recent report I have found regarding compulsory sterilization for mental deficiency in this country indicates a decline from 1,643 cases in 1943 to 643 in 1963.

I believe the laws that single out "mental retardates" -- or any stigmatized group, clearly identified as such -- for special restrictions in sexual or family life violate the United States Constitution. The simple existence of laws that aim at vulnerable, stigmatized groups as such presents intolerable dangers of abuse and over-use. The mentally retarded are not the only stigmatized group against whom special sexual and familial restrictions are directed. The retarded share this distinction with those whom we label "mentally ill" and "criminal." Virtually all state laws authorizing compulsory sterilization of mental retardates apply equally to the "mentally ill" and about half of those laws also apply to "hereditary criminals."

The stereotypes that are projected onto these deviant groups are remarkably similar in attributing dangerous sexual appetites. The Nebraska Supreme Court, in its 1968 opinion upholding the constitutionality of the state's compulsory sterilization law for institutionalized mental defectives, stated: "It is an established fact that mental deficiency accelerates sexual impulses and any tendencies toward crime to a harmful degree." This statement has of course no empirical support. As an expression of popular prejudice, however, the statement could apply equally to those considered "mentally ill" or "criminals."

The prevalence of sexual imagery and fears regarding blacks in this country is a related phenomenon. The laws which forbade intermarriage among blacks and whites -- rationalized by a potpourri of genetic and social arguments -- has a close kinship with the restrictive laws applied to the mentally retarded. Indeed, one important attribute of slave status in this country (but not, interestingly enough, in the Latin American countries where slavery also flourished) was that slaves were forbidden to marry, and familial ties between parent and child were disregarded as a matter of course. Mental retardates share with these other stigmatized groups the popular perception of "less-than-humanness" and they, like these other groups, become the target and repository of a cluster of fears that are felt to assault our "humanness" in general. Among these fears, unabated sexual appetite ranks high.

This special vulnerability of mental retardates as an irrationally feared and stigmatized group has important legal implications. It means that, as a group, they warrant particular protection most notably against the operation of legislation aimed at their sexual and child-rearing behavior. Mental retardates are "a discrete and insular minority . . . [against whom prejudice tends seriously to curtail the operation of those political processes ordinarily to be relied upon to protect minorities, and . . . [on whose behalf] a correspondingly more searching judicial inquiry [may be called for]." For blacks -- another such "discrete and insular minority" -- the Supreme Court has increasingly done battle. In this pursuit, the Court has ruled unconstitutional the state laws prohibiting marriage between blacks and other races in a case appropriately denominated Loving v. Virginia. This result was dictated by a prior series of Supreme Court holdings (beginning with the famed 1954 school segregation case) which invalidated any form of state action that singled out blacks as a group for special derogatory treatment. Whether or not a similarly broad principle should be followed by the courts to protect mental retardates, their rights to sexual freedom should be judicially protected. The special status of family and sexual conduct in this society has been acknowledged in various Supreme Court cases as fundamental rights "to marry, establish a home and bring up children," the right of "privacy surrounding the marriage relationship," "the right to satisfy [one's] intellectual and emotional needs in the privacy of [one's] own home." The Supreme Court has recently stated,

> If the right of privacy means anything, it is the right of the individual, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child.

These familial and sexual freedoms, which the Court properly sees as the core of the right to privacy, are drastically and wrongfully infringed by such laws as sterilization and marriage prohibitions directed specifically against the mentally retarded.

Some state legislation imposes disabilities only on a specially designated class among mental retardates. The Utah Code, for example, provides for compulsory sterilization, among the retarded, only for those who are "probably incurable and unlikely to be able to perform properly the functions of parenthood." This apparently more limited application does not, in my judgment, save the statute from the vice inherent in all of the restrictive

legislation that singles out the mentally retarded as such. However uncertain our capacities to distinguish among good and bad parents generally, this society, and its officialdom, clearly is in the thralls of a strongly irrational attitude regarding the sexuality of the mentally retarded. Our officials share the incapacity of most people in this society to look at the retarded without inappropriate fear or pity, to look at them with sufficient clarity to permit sensible differentiation among them. Because the mentally retarded as a group are so readily victimized, because they are a vulnerably "discrete and insular minority," compulsory interventions in their childbearing activities which might be tolerable for the general population is constitutionally intolerable if limited to the retardate group alone.

Justice Holmes' famous -- indeed, notorious -- opinion for the Supreme Court in 1927 upheld a state compulsory sterilization law with the aphorism "three generations of imbeciles are enough." But Holmes' Court wrongly failed to appreciate their special role in protecting vulnerable minorities. A 1942 Supreme Court case, invalidating a state's compulsory sterilization law for habitual criminals on grounds that it made irrational distinctions between those criminals who should and those who should not be sterilized reveals a different, and more enlightened, Court attitude. The Court has not yet administered the coup de grace to these laws, though it appeared ready to do so when it took jurisdiction over the 1968 Nebraska Supreme Court's decision, noted earlier. The Nebraska Legislature, perhaps reading between the lines of the Court's writ, repealed its compulsory sterilization law before the Court had an opportunity to rule on its constitutionality. When the Court is finally given the opportunity to rule on such laws, I have little doubt that it will overturn them.

But this Court action, when it comes, will remove only the easiest problem. Even if my argument here is accepted, and the courts strike down all sterilization, marriage prohibitory and child removal laws specifically limited to the mentally retarded, that will eliminate only the most obvious of legal impediments afflicting mental retardates. Most notably, such court action will not invalidate child abuse and neglect laws which generally authorize compulsory removal of children from their parents. Although these laws apply to the population at large, I believe that they will fall with particular harshness on parents who, by their residence in sheltered homes

for the "mentally retarded" (often supported by public funds and thus highly visible to other public agencies), appear to flaunt their diagnostic label and thereby remain peculiarly vulnerable to community restrictions on sexual and child-rearing activities.

Child abuse and neglect laws of virtually every state are sufficiently broad-gauged to authorize compulsory removal of a child from a parent who is regarded as incapable of child-rearing merely because of mental deficiency. The Minnesota child neglect statute, for example, authorizes the state to take custody of any child "whose . . . condition, environment or associations are such as to be injurious or dangerous to himself." Inevitably the fears and prejudices that stigmatize mental retardates will intrude on the judgment of court and social agency personnel who will apply these statutes.

But though these open-ended statutory invitations to state intervention bring this risk of abuse, these statutes cannot be overturned on this ground alone. Numerous procedural guarantees -- such as right to counsel and opportunity to rebut all adverse evidence -- should be provided to all parents, including the mentally retarded, who are subjects of child abuse or neglect proceedings. But the statutory standards for state intervention cannot be so narrowly defined as to eliminate the possibility of misuse without inappropriately withholding the possibility of state intervention to help children in serious jeopardy from inadequate parenting. The opportunity for victimizing the mentally retarded in the application of child abuse and neglect laws must, regrettably, remain a reality.

This special vulnerability creates an obligation on the part of those planning new modes of introducing retardates into community life to defend their clientele -- preferably in my view by appending special plans for intensive child-rearing services to any plans for sheltered community living in which normal heterosexual contacts are envisioned. Unless those who specially care for the mentally retarded can convincingly attest to the rest of the community that the children of retardates are being well-bred, it seems that these children will be lost, lost in many ways. The need for these special child-rearing programs seems to me even more urgently required than the need for similar programs for those parents in the "normal" population who share the child-rearing disabilities of a portion of the mentally retardate population. The label of retardation threatens loss to all who

bear it; it is to protect them, as much as to protect those among the retarded population whom all "right-thinking people" would agree are incapable parents, that specially protective programs are needed.

A second problem must also be faced. Statutes that authorize voluntary sterilization, abortions, or relinquishment of children, present quite troublesome issues regarding mental retardates. The argument for compulsory sterilization of mental retardates founders in part on the uncertainty of genetic predictions. But new advances in intrauterine diagnosis -- which permit wholly accurate detection of Down's syndrome and other kinds of developmental anomalies -- changes the context of the argument.

It seems unthinkable that the state would ever compel therapeutic abortions for the general population, even if developmental defects were detected in utero. But therapeutic abortions for mothers who so choose are increasingly accepted in state laws. Should maternal choice also govern if the mother is herself "retarded"? In what ways can the "retarded mother" be adequately helped to exercise choice? Should someone exercise choice for her?

No matter how euphemistically we describe this last alternative, it is compulsory abortion limited to those whom we label "mentally retarded."

Legal authority to make such choices on behalf of mental retardates appears available in the guardianship laws in all states, which authorize the appointment of custodians for, among others, "mentally deficient" persons who are not institutionalized but are nonetheless regarded as incompetent to handle some portion or all of their affairs. The potential for abuse of these guardianship laws is clear.

A case recently decided by the Kentucky Supreme Court should serve as a warning. In Strunk v Strunk, the court authorized the appointment of a 27-year old institutionalized retardate's mother as his guardian in order to permit her to consent on his behalf to remove one of his kidneys to donate to his otherwise doomed, intellectually normal older brother. The court did not seem troubled by the mother's at best necessarily ambivalent role in making this decision for her retarded son.

But no matter who is given such power of choice over child-rearing for a retardate, similar conflicts -- whether conscious or unconscious -- are bound to be provoked. Can, for example, an administrator of a sheltered

home for retardates address the question whether one of his charges should abort her genetically flawed child, or surrender her normal child, without being influenced by the impact of his decision on community approval of his enterprise generally and the implications of that approval for the welfare of all his charges?

I believe that a retardate who might require a guardian to make, or assist in, this choice is entitled at least to someone who is sufficiently trained and sufficiently detached to view the matter from the retardate's perspective, with other conflicting perspectives banished to as great a degree as possible. The laws, and the judicial personnel involved in, authorizing appointment of guardians for mental retardates are not sufficiently sensitive to these kinds of conflicts of interest that work against the deserved freedoms of mental retardates. If we intend to offer greater freedoms to those retardates whom we no longer institutionalize, we must assure that this problem is adequately addressed.

I have no easy answer to these questions. There is serious danger that generally applicable child neglect laws, for example, will be discriminatorily applied against the retarded. But I am unwilling to conclude that this danger is so great that we must leave the decision with the mother -- no matter what her capacities -- regarding, for example, whether to surrender her child for adoption. Reliance on parental choice in all child-rearing matters must be our primary goal. But I believe there will be cases in which such reliance would be misplaced, and detrimental to the child's interests.

We cannot blithely trust legal institutions to make wise and sensitive discriminations in applying authority to override parental choice. But in my judgment we cannot wholly deprive the state of this authority to protect against its abuse. We must instead maintain constant vigilance to protect the interests of those among us, including the mentally retarded, who are always vulnerable to excessive deprivations by those purporting to act for their benefit.

It is likely that courts can be persuaded to apply the Constitution in order to invalidate the injustices that previous generations of law-makers have imposed on the mentally retarded in their sexual and family lives. It is equally likely that, unless careful thought and planning is undertaken in conjunction with efforts to bring the retarded into community life, the same injustices will be imposed on the mentally retarded under new legal guises.

WORKSHOP REPORTS

GROUP I

Mr. Richard Zipper
(Group Reporter)

Group Leader: Mrs. Martha Moersch Resource Person: Mrs. Virginia Nordin

Our group clearly recognized that court action in many cases is necessary. Our focus related to legal aspects, such as legal practices and policies. We were concerned with the apparent inequities in minimum wage laws, zoning restrictions, and other pressing issues in the legal area. We recognized that the primary problem that continually arises is one of funding. When a bill is finally passed, the question arises: where does the money come from to implement the bill? With regard to the Mandatory Education Bill that was recently passed in Michigan, funding is mandated by the court. It's not a question, in this instance, of whether or not funding will be provided, but where are you going to get the money. We also noted that some of the laws that were set up to protect the retarded during the nineteen twenties may, at this point in time, work to hinder the progress of the retarded. The group had one concrete suggestion to report out. The suggestion was that the Associations for Retarded Children are perhaps the most logical advocacy group because these Associations are voluntary organizations. There is also a great need for persons working in the field of mental health or educational rehabilitation to consult lawyers who can give the kind of legal advice that is needed. I think it was fairly well accepted that legal advice may well be the most important thing that we can utilize at the present time. Perhaps, short of suing, we must be ready and willing to take a stand, whether it's through a particular group or the formation of a new group. Using legal procedures, therefore, may well be the very next step in provision of full rights for the retarded and for the handicapped.

GROUP II

Mrs. Phyllis Manson
(Group Reporter)

Group Leader: Dr. Julius Cohen Resource Person: Mr. Robert Burt

We stayed very close to Dr. Burt's topic which was sterilization and the sexual rights of the retarded. The laws related to sterilization of the retarded seem primarily concerned with limiting procreation of unwanted children who "inherit defective genes and become state charges." This appears to be the rationale behind the law. It is very difficult to determine how often the law is used or invoked because reporting is not done on a consistent level. Voluntary sterilization is generally not available to the retarded after they are 18 years old. However, this may be possible after guardianship has been established for them. Therefore, those who are over 18 and would like to be sterilized must have somebody else make that determination for them, despite the fact that studies show that the retarded, in many cases, can parent in a totally stable and warm manner. Dr. Burt pointed out that if a retarded child has been sterilized, without his consent, at 18 he can file suit against his parents. Under 18, he can be referred to lawyers who are available for the protection of minors against the parents. The group also discussed the factor of punishment in the state institutions for heterosexual behavior and how this may reinforce homosexual behavior. Homosexual behavior is more or less ignored. Institutions see heterosexual behavior as normal but punishable. It equates retardation and homosexuality as abnormal. In accepting retardation the institutions tend to accept homosexuality as a concomitant of retardation and ignore it. Homosexual behavior, therefore, is condoned as part of the "deviancy" of retardation. Abortion was discussed and it was the feeling of the group that for many of the retarded this would not be a "solution" because of the trauma involved. However, I think we all agreed that for most, abortion would probably be preferable to sterilization. Then the question was posed, "Are parents or guardians afraid of sexual experience among the retarded?" There were some interesting answers from some fathers on the panel. It was generally agreed that parents of so-called "normal" children have considerable problems with this issue. It seems that the parents of the retarded are looking for a more simple resolution to the dilemma and probably think of sterilization as a panacea. Because of this, the rights of the retarded individual may need much more protection than the rights of the normal person. Another point mentioned was that our culture supports the idea that sexuality itself is an earned right and consequently a bias is felt that the so-called "defectives" have not earned the right to

that particular pleasure. We agreed that we do not have adequate protections set up for voluntary sterilizations and there was a recommendation for a review of the laws concerning sterilizations. Dr. Burt suggested that the Michigan Association for Retarded Children or similar organizations contact the Attorney General's office to express their concern about the recording of sterilization. We need to ask for his cooperation because we really have no figures to go on. The group discussed preventive tools for mental retardation but I think our final conclusion was that at this time in history we should be looking to ourselves concerning our feelings about deviancy. We all have to ask ourselves, "Why am I judging?" It becomes tempting with the retarded to pass judgment. The alternative is to abolish all judgments. It's a very thin line to walk. It appears that we should be offering handicapped individuals numerous options or alternatives rather than simply labeling them as deviants.

GROUP III

Mr. Charles Fogelman
(Group Reporter)

Group Leader: Dr. Richard Darnell Resource Person: Dr. William Rhodes

Our group had a pretty academic discussion sequentially covering three things. We talked about the topic of labeling which is where we started. We talked a bit about general and specific issues of deviancy and then we talked about the question of advocacy since that was the title of the conference. In terms of labeling we thought that there were probably good labels and bad labels. An example of a good label is the inclusion of the words "mental retardation" in the title of the Institute because without that particular label we probably would have no funds coming to us from the federal government. An example of bad labels, which is, of course, much more serious, is again the words "mental retardation" and "mentally retarded" and all of the evaluative connotations which that phrase has. We talked about labels as a way of allowing society to maintain its role expectencies and as a way of allowing it to deal with "people who are different." Labeling is a way of allowing communities to deal with deviant individuals. We decided that we definitely need a change in labels and although we didn't

make any radical suggestions, such as simply abolishing labels, we did say that one of the things we could do was to re-educate the public at large as to what the labels mean. We thought it was not so much the labels themselves that were at fault, but what we understood the labels to mean or what the general public did not understand the labels to mean and how they misused them. Another proposal was using an entirely different set of criteria and therefore a different set of labels. At the same time that we are developing this new set of labels we should educate the population along the way. Another possibility is to move into the area of advocacy starting with what we have now. The group then moved into a discussion of deviancy in general. We decided that labeling was a means of dealing with a threat of difference. We, as professionals, are particularly threatened by deviant individuals, particularly retarded individuals, because we value our own intellectual functioning so much. When we see someone who cannot function intellectually the way we do, we sometimes are most threatened by that and maybe it's we who therefore must maintain those labels through time. We talked somewhat about cross-cultural differences in deviants and in the way we deal with deviant populations. From there we moved into the question of how change comes about, which led us to talk about advocacy. Is advocacy necessary? Yes! We who are attending the conference agreed that some system of advocacy should be established. We felt the family should be the first advocate for the child and the first recourse. However, the community, community agencies, service people and professionals in the communities and on a state level should also be advocates. Advocacy can be institutionalized. It can be bureaucratic. Advocacy can be personal, radical or individual. One of the things about advocacy is that it shouldn't be the kind of thing where you say, "O.K., look, you can't help yourselves so we're just going to pull you along." Advocacy should be more of educating people to be able to help themselves. It should be a positively oriented process rather than something which demeans the dignity of the individual involved. Finally, we decided that particularly for us as professionals we need to change our view of ourselves and what we consider our role to be. Perhaps we should become trainers of advocates, advocates ourselves, or, at the very least, inciters to advocacy, because in many ways it has been the professional who has been responsible for the labeling and for the manner in which our services "treat" the retarded today.

GROUP IV

Dr. Harry Overline
(Group Reporter)

Group Leader: Dr. Leonard Burrello Resource Person: Mr. Lynwood Beekman

Our group probably initiated and finally summed up with a number of questions and I'm reminded of the story of the farmer who went to a psychiatrist and he said, "What do you charge?" The psychiatrist replied, "I charge $50 for every two questions." The farmer said, Well, that's rather expensive isn't it?" The psychiatrist replied, "Yes, what's your next question?" The importance of asking questions I think is really not superficial. The raising of questions demands attention to an issue. We then move toward testing out the questions and finally, hopefully, coming up with conclusions. Speaking of questions, I'm also reminded of Gertrude Stein's comments on her deathbed. She was in a coma and she kept saying to herself, "What is the answer?" She kept trying to figure out the enigma of life. "What is the answer? What is the answer?" she asked all night long. Finally, in the morning, just before she passed away, a smile came over her face and she said, "What is the question? What is the question?" I think too often we're really concerned with red herrings. We expend a lot of energy perhaps on things that aren't really the focus of what we're after. I'd like to report on some of the questions that our group raised, but did not always answer. Lynwood Beekman expanded upon the implications of the recently filed suit in Detroit. We have the Mandatory Education Bill in Michigan so the present litigation was not initiated to stimulate the adoption of legislation but rather to speed up or to implement mandatory education. He also mentioned another very strong influence in the state of Michigan and that, of course, is the suit recently filed by Kelley and Milliken on the realigning of the financial situation in the state. He also made note of the fact that the National Educational Association has initiated petitions with the idea hopefully of realigning equal educational opportunities for all youngsters in Michigan. The implications of that are not just socially based. Obviously the concern is for equal education for all children, black or white, poor or rich, handicapped or not handicapped. One of the issues that's probably

going to be a very important one and is tied up in the next steps of mandatory education, is the matter of funding. A point was made that parents would be involved in the system of checks and balances so as to assure that these programs are indeed offered to handicapped children. The question was then raised as to how deeply and intimately should parents be involved ? A very strong case was made for having parents involved in all phases, from the initiation phase of referral, during the diagnostic phase, and also during the remediation and placement phase. Their role should not be just advisory but rather they should be involved in the decision-making process. Parents may even be involved with vetoing the placement consideration as recommended by a group at school or by mental health officials. Another issue raised was relative to the fact that mandatory education covered children and adults up to 25. Why is it arbitrarily cut off at 25 ? Why not 24 or 23 ? What happens to the people we're talking about at 26 ? The commitment under the law only goes from 0 to 25. The group raised the issue but we had no answer. Another question came up with regard to the age of majority. What does the age of majority mean in terms of the voting power ? Do retarded people have the right to vote ? Obviously, they do. What are the implications ? Do people in institutions have the right to vote ? What are the implications for the right of the retarded to vote and the potential power to effect changes within the state legislature and future bills ? No one was able to answer that. Only time will tell. We also discussed deviancy and the ecology of deviancy. A point was made that ten years ago there were "hippies" and "freaks" walking around. Today many youngsters would fall into that category. We don't even use the word "freak" or "hippie" anymore. These people are often on the cutting edge of society and what may have once been seen as weird or bizarre has now become a kind of status quo. The group also raised a question about society's genuine commitment to education of the mentally retarded. Is it just a token kind of commitment ? Are legislators being forced to pass legislation but really feeling it viscerally ? Will their future action reflect the level of commitment ? Are they going to put their money where they're putting their legislation ? The essential question really becomes this: if our society really did respect individual differences, the term "mental retardation" would cease to exist. Its the extent to which we do not respect individual differences and have no patience for it that the problem exists. If we really believe that people are individuals and if we acted as if we believed that, perhaps we wouldn't be sitting here today.

GROUP V

Mrs. Ann Zuzich
(Group Reporter)

Group Leader: Miss Mary Jo Huetteman Resource Person: Dr. Lawrence Turton

Our group initially discussed the right to treatment in a state institution. This led to a need to clarify what we mean by treatment. Dr. Turton defined it in terms of the decision making process and the way that treatment was viewed within that decision. There was considerable discussion about where does the right to safety enter into that whole concept of the right to treatment. We gave recognition to the need that residents of the state institutions have for safety and security. There was a considerable amount of discussion about the Associations for Retarded Children and the current trend of these organizations becoming more professionally oriented since many of their most articulate members are professional people. Some concern was expressed that the Associations for Retarded Children were losing some of their impact as they became more professional. Concern was also voiced about professionals and parents both having an inability to be very aggressive about expressing their views regarding institutional care because they are fearful of retaliation. Professionals in the institution are sometimes threatened by parents. Instead of a cooperative endeavor between professionals and parents, there is often a dichotomy that really impedes the programming for the residents. It was felt that professionals frequently have a need to achieve some personal satisfactions in their work and that often there is a kind of manipulation of the whole system to provide them with these personal satisfactions. Professionals see that the problems in the system continue to exist despite their efforts. When they are fully aware that they are having very little impact on the total system they become frustrated. The group also brought up the question of foster homes and the need for the development of more homes. We touched on the need to educate the community to better understand the kinds of individuals that are being considered for placement in a community living situation. What is the criteria for returning

mentally retarded residents in state institutions to community living situations? There was a plea for more definite guidelines relative to the selection of residents who are to be returned to the community. The group also discussed the criteria used for admission to state institutions. We need to define more clearly the criteria for both admission to and discharge from the institution. We also discussed how we tend to disregard the impact of separation on the mentally retarded individual as we move him throughout his lifetime from one setting to another. We sometimes drastically change his way of life and give very little consideration as to the effect that these changes have on his life style. These changes may defeat his rehabilitative program. In each separation he may regress. We discussed in depth how the parent and the professional can relate to one another in some kind of a profitable way for the mentally retarded individual. Someone suggested that the administrator of the institution should have six months relief from his job so that he may have more contacts with individual mentally retarded residents. He may then have a different view of his job when he returns to his desk. Both parents and professionals questioned what the service delivery system was trying to do and questioned our impact on the system. They thought that perhaps the reason why we have so little impact is due to the fact that we really don't know what are the objectives of the system. We finally stated that we may be copping out by saying that "the reason things are so bad is that it's the system out there and not us here sitting in this room who may be at fault." We came up with some recommendations. Number one was that this conference should be given exposure through the press and the media not just in Washtenaw County but across the state. The other recommendation was that representatives from this conference communicate with the representatives from the Associations for Retarded Children for the purpose of pursuing a plan to cooperatively mount a campaign of community education to support the community placement concept and to encourage advocacy for the mentally retarded.

GROUP VI

Sister Paraclita
(Group Reporter)

Group Leader: Mr. Harvey Zuckerberg Resource Person: Mrs. Mary Wagner

Our group discussed the following areas: the financial support of the retardate, his employment, citizenship status in the county, guardianship, and the right of protection from abuse and exploitation. Many of these were projected as questions rather than answers although there are some answers proposed and given. In regard to the question of financial assistance, the question was raised as to whom can we go to get financial assistance? The Michigan Association of Retarded Children does have a brochure providing some of this information for parents for retarded children and adults. Financial assistance can be secured from the Department of Social Services under programs of Aid to the Disabled. In our discussion about employment, we noted that the national labor movement does support equal opportunities for the handicapped. However, many local unions are violating this. The point was raised that in establishing a day care of a community placement center the retardate has a right to utilize all the avenues that normal employees use to seek employment. They should have access also to recreational and the usual community services and activities. The question was posed, "Are the retarded citizens of the county in which they are residing or citizens of the county in which their parents are living?" If they are under the age of 18, it is presumed that they are citizens of the county in which their parents are residing. At the age of 18 are they "residents" in the county in which they are living? These questions were raised with regard to establishing community based residential centers of developing employment programs for those retardates who may be released from state institutions or in institutional situations. It was felt that their residency status may affect program planning. With regard to guardianship, it was stated that Michigan does not yet have a protective guardianship statute. It was felt that there should be a distinction made between a guardian and an advocate. The guardian, of course, is the protector of the person and/or the estate as the case may be, whereas the advocate is more or less an ombudsman or a watchdog for the well-being and special interests, not necessarily legal, of the retardate. A question was raised whether or not guardianship would cover civil rights, money, property, and protection of the person when the retardate is in a community placement home. A guardian is appointed in placement situations when it is deemed necessary. Usually the State Department of Social Services would take over on the legal aspects of protective custody of a retardate who has no legal guardian. The group also discussed the need for protection from abuse

and exploitation. A problem presented was that the retardate is a very poor witness, especially in cases of rape or a paternity suit. Because of the fact that the retardate may make a very poor witness, recourse would probably have to be taken then outside the legal systems. It was suggested that probably support and help could be given through citizen advocates or through the big brother and big sister programs. Another proposal made is that many of these problems indicate a need for expanded programs in sex education for the retarded. Programs in this area would reduce the vulnerability of the retardate.

GROUP VII

Mrs. Ida Gordon
(Group Reporter)

Group Leader: Mr. Herman Dick Resource Person: Mrs. Marjorie Kirkland

Our discussion opened with an analysis of what dignity means for the retarded, and how unconsciously we professionals and parents both take away a lot of the retarded's right to self determination compared to what we allow so-called other "normal" teenagers. It seems that the parent or the professional can never win. If they overprotect the retarded, people critize them. if they underprotect people say that they neglect the poor child. You can never achieve a happy medium with the general public. We discussed at length the role that parents and professionals can play in allowing freedom for the handicapped. To give them dignity, we have to look within ourselves and what priorities we have and what we expect of them. Can we project how much they can achieve in life? Do we see their limitations or do we expect too much from them? Do we accept them for just what they are? If we really do, we can given them a sense of self dignity without always making them feel inadequate. What we want for the retarded is to give them dignity. The group also discussed a new citizens advocacy program which is being implemented in Kalamazoo, Michigan. In Lincoln, Nebraska there is also a successful program started there. In Kalamazoo they are endeavoring to get the public interested in befriending the retarded, standing by when they have problems. It was brought out by one of the members of our discussion group that there is need for the mentally retarded to do things for other

people. We must allow them to help the community and to help other people. This is also important for their sense of dignity. They should not always be having something done for them. We should try to put them in a position where they can help others. We concluded with the thoughts expressed by a mentally retarded young man. He stated some things that he wanted as a retarded person. He presented some very interesting thoughts. He said that he would like people to listen to what he has to say, not always passing his opinions as not being relevant. He wanted people to be honest with him. He said, "If you do this, it will build up our ego and make us feel like a person." Treating the retarded in this way gives them the dignity and the desire and the courage to make progress in other fields of endeavor.

ADVOCACY CONFERENCE EVALUATION REPORT

Institute for the Study of Mental Retardation and Related Disabilities

June 2, 1972

PURPOSE AND FORMAT OF THE CONFERENCE

Brief panel presentations at the morning session and small workshop groups in the afternoon session brought together professionals, parents, and retarded adults to examine the concern regarding the legal and human rights of the mentally retarded. Methods of securing these legal and human rights for the mentally retarded were proposed. Strategies for dealing with the violation of these rights were developed. The focus of the areas discussed by the panelists and in the workshops were: 1) Advocacy; 2) The right to dignity; 3) The right not to be labelled; 4) The right to financial assistance; 5) The right to education; 6) The right to community services; 7) The right to treatment in state institutions; 8) The right to marry and the right of choice regarding sterilization; 9) The right to legal process and legal redress.

In an effort to insure that many different areas concerning legal and human rights were covered, participants were assigned to one of the afternoon workshops in which the morning panelists served as resource persons. The workshops were structured to cover the topic of the panelist during the first 40-50 minutes and then to cover other areas of concern to the participants as they raised them.

A total of 143 persons representing professionals, parents, and retarded adults attended the Conference, which was held at the Rackham Auditorium, University of Michigan, Ann Arbor, Michigan.

EVALUATION OF THE CONFERENCE

Fifty of the participants filled out and returned feedback forms for the Conference.

Panel Presentation

Forty-five cited the panel presentations in the morning as being what they liked best about the conference while five mentioned the afternoon workshops. Those who cited the panel presentations focused in on the wide variety of topics presented and the expertise of the presentors in discussing the topics. Though all panelists and each panel topic were cited as valuable, the presentations regarding educational rights, legal rights, and the labelling issue were most frequently mentioned in this respect. The legal

and educational rights of the retarded were frequently pointed out as being the most urgent of the rights that are being violated. However, the most frequent response (25%) cited "The right to dignity and respect from which all other rights follow" as being the most urgent.

Workshops

Approximately 25 respondents or 50% mentioned the free discussion and exchange of ideas as being the most valuable aspect of the afternoon workshop sessions. The contributions of the group leaders and resource persons were also mentioned as valuable.

Suggestions for Improvement

The most frequently suggested improvement (25%) was to have more time for the Conference as a whole and particularly for the panel presentations and for discussion following the panel presentations. (Some of the Panelists, however, indicated that the time limit on their presentations helped them to effectively organize their material and time. The time limitation also permitted a broader range of content coverage.) Other frequently mentioned suggestions included having the participants in the workshop choose a workshop of interest to them instead of being assigned to one. (Assignment, however, insured that the participants in the workshops represented various disciplines and equalized the number of members in the various groups.) It was suggested that the workshops should be slightly more structured and task oriented. Six respondents indicated that the conference was excellent as it was and had no suggestions for improvement.

Recommendations for Action

Fifty per cent of the respondents viewed the education of the public regarding the rights of the retarded as the next step in achieving the aims of the Conference. It was indicated that there was a need for information dissemination through media coverage. It was stressed that an advocate stance needed to be undertaken by individuals as well as through groups and organizations. The Michigan Association for Retarded Children was often pointed to, by twenty per cent of the respondents, as an important advocacy avenue which should be utilized.

SUMMARY

The overall evaluation of the Conference was extremely favorable and indicated

that the Conference had focused on areas of importance and concern. This was also indicated by the most frequently suggested improvement, that of allowing more time for the conference as a whole. There was widespread approval of the content and format of the Conference with the panel presentations receiving particular commendation.

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APPENDIX

Discussion Group Leaders and Group Reporters

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